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Executive Summary

Indigenous peoples across Canada who are living with advanced, progressive, chronic, and terminal illnesses wish to receive palliative care at home or in their First Nations or Aboriginal community, where they are surrounded by family, friends, culture and spirituality. However, the majority of Indigenous peoples currently die in urban hospitals or long term care homes. The hospital is the most expensive setting of care and an inefficient use of health services, as caring for terminally ill patients in an acute-care hospital is estimated to cost over 40% more than providing care in a hospital-based palliative-care unit. This is more than double the cost of providing care in a hospice bed and over 10 times more than providing at-home care. Ontario has made significant commitments and investments to support the development of a comprehensive strategy for palliative and end of life care in the province. These commitments include improving health outcomes for Indigenous people in Ontario, including fair and equitable access to high quality and culturally safe palliative care.

The Aboriginal Health Committee of the South West LHIN is undertaking an Aboriginal Hospice Palliative Care planning project to enhance and support the development of an Indigenous informed approach to address the Hospice Palliative Care and End of Life care for Aboriginal and First Nations communities located within the South West LHIN.

This research, with more than 25 key informants, two focus groups as well as the Reference Panel guiding this first phase of the South West Indigenous Hospice Palliative Care, substantiated what previous studies have already documented. First and foremost, Indigenous people, First Nations communities and Aboriginal organizations in the South West LHIN solidly affirmed their readiness, capacity and desire for Indigenous palliative care services based on principles of self-determination, equity and social justice intended to improve quality of life for Indigenous people who are dying and their families.

This report has found that culturally safe palliative care services are not equally accessible to Indigenous peoples, particularly those that live on reserve. The reasons for this permeate every step of the palliative circle of care and are entirely preventable. Research participants shared that the diagnostic process for palliative care is flawed, as it does not occur early enough and potential patients must satisfy rigid requirements in order to access care. Patients and their families are extremely unfamiliar with the palliative process and all the agencies involved. There is no education surrounding what to expect, who to call for support, or the inherent challenges in becoming a caregiver to a family member. It was evident throughout the interviews that Indigenous peoples are routinely denied access to palliative services if they do not have a working phone, internet or transportation to appointments. Indigenous peoples are also denied services after 5 pm if they live on reserve, while those that live in urban areas are able to access a caregiver at these times. If the palliative patient has existing family supports nearby, then they are denied services, as the families are expected to shoulder the burden, regardless of their situation.

The delivery of palliative care to Indigenous peoples is currently problematic as well. This research shows that there is an endemic lack of staff to meet the demands of palliative care to Indigenous peoples. The staff are not able to meet the needs of the communities and many lack the updated palliative care training necessary to provide excellent care. Research participants also indicated that there is a severe communication issue between service providers, which prevents seamless service delivery in the palliative circle of care. The inability to create a good working relationship among the
many service providers has been shown to have consequences for the palliative patient. There are even discrepancies between the statistics of Indigenous palliative care patients. For instance, participants shared more than 40 examples of chronic patients who became palliative and wanted to die at home, however the South West CCAC acknowledged that they had only provided end of life care to 2 or 3 patients in the past two years.

One of the most notable conclusions of this research is the significant lack of cultural safety for Indigenous palliative care patients. This can take many forms, including a refusal to attend Indigenous palliative patients if they need care on reserve after 5 pm, ignorance of spiritual and cultural needs that are so important at the end of life, a lack of knowledge of Indigenous histories, rights and experiences, and well documented discrimination incidents. Participants maintain that the non-existent cultural safety in palliative care helps to continue the historical mistrust of non-Indigenous health institutions and organizations and has a detrimental effect on the quality of end of life care for Indigenous patients.

This report has a total of fourteen recommendations for an Indigenous Hospice Palliative Care program, based on numerous interviews, focus groups, literature reviews, and patient experiences. Participants felt that the program must be based on Indigenous understandings of health, illness, birth, and death which differ across communities and linguistic groups. Also, the program must be based on Indigenous control and implementation of a community capacity development approach that emphasizes the engagement of Indigenous community members and incorporates community cultures, strengths, and resources.

One of the primary recommendations of this report is that the South West LHIN fund an Indigenous Hospice Palliative Care inter-professional team (collaborative) at SOAHAC to improve patient and system-level outcomes to be composed of: Registered Nurses, Nurse Practitioners, a Social Worker (with experience in grief and bereavement), a Mental Health Worker, a Traditional Healer, a Personal Support Workers (PSWs), Occupational Therapists/Physiotherapists and Physicians. Another key recommendation is that additional Aboriginal Patient Navigators be hired to provide community outreach and case management through the Indigenous Hospice Palliative Care program. The goal will be to work with palliative clients and their families to introduce the Indigenous specific services, traditional practices as well as linkages to mainstream services that will bridge the gaps for positive patient health experiences. Also, this report makes an urgent recommendation that all service providers working with Indigenous palliative clients and families be educated on the complexity of Indigenous Health issues, Indigenous rights to determination in health and be trained on Indigenous histories and cultural safety.

Other recommendations include establishing early relationships with chronic patients, improving Advance Care planning, and ensuring that the Indigenous Hospice Palliative Care Model be designed on low threshold principles intended to screen patients into the program rather than screen them out. This report also advises that access to palliative services are increased and barriers are removed. This means increasing transportation services to appointments, ensuring e-Shifts, and increasing Personal Support Workers in First Nations.

Overall, this report has consolidated previous research and undertaken many interviews and focus groups, in order to provide a comprehensive understanding of the current state of palliative care in the southwest LHINS. A clear pathway has been provided to enhance and support an Indigenous informed and led Hospice Palliative Care approach for Indigenous people in the South West LHIN.
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INTRODUCTION

“Building confidence and trust while respecting self determination is essential to the provision of Indigenous hospice palliative and end of life care.”

The Aboriginal Health Committee of the South West LHIN is undertaking an Aboriginal Hospice Palliative Care planning project to enhance and support the development of an Indigenous-informed approach to address the Hospice Palliative Care and End of Life care for Aboriginal and First Nations communities located within the South West LHIN.

Palliative care is a special type of healthcare that provides care, comfort and support to individuals and families who are living with a life-threatening illness. It is for people of all ages. The focus is on the person and not the disease. It is about improving the quality of life at a time when the goal is not to cure. Palliative care involves a wide range of services that can be personalized to meet the needs of the person living with a terminal illness and their family. A caregiver group of healthcare professionals, family and friends make up the Palliative Care Team. Palliative services may vary but generally include: pain and symptom management; social and emotional support; spiritual support; caregiver support; volunteer support; bereavement support and links to other resources (Lakehead University, 2015).

The majority of Indigenous people would prefer to receive their palliative and end of life care at home where they are surrounded by family, friends and culture. This finding is similar to the stated preferences of Canadians in general and thus should not be surprising. In contrast, most Indigenous people

HOW THE PROCESS WAS ORGANIZED

We held two focus groups with:

- South West Home and Community Care Network Association
- South West Regional Cancer Program

Five meetings were held with the Aboriginal Hospice Palliative Care Reference Panel

Two meetings were held with SOAHAC and the South West LHIN

A total of 25 Key Informant interviews took place

Before each meeting the process of the Indigenous palliative care program development was shared and assessed the community readiness as developed by the Lakehead University Improving End-of-Life Care in First Nation Communities research project

1 In this report we use the term Indigenous as an all encompassing term to represent First Nation, Métis, Inuit, or Non-Status peoples. We also use the term First Nation to refer to Indigenous communities who recognize themselves as a First Nation. We use the term Aboriginal when it is used by organizations or non-First Nation governments, such as urban Aboriginal organizations.
Currently, many Indigenous people die in urban hospitals and long-term care homes. Coming home to die has particular importance for Indigenous people, whether that home is in the urban setting or the First Nation. It is important for Indigenous people to be surrounded by family, friends, culture, and spirituality. Removing end-of-life care out of the Aboriginal or First Nation community disrupts family life and creates emotional, social, spiritual, and economic burden. A person dying outside of the community creates a barrier to normal grieving for family and community. Indigenous people understand that grief is an important process, and disruptions in appropriate grieving have negative effects on overall community, social, and economic well-being.

Dying at home is not only the preferred option for most Indigenous people; there is also a strong economic rationale for providing palliative care in their home, whether in First Nations communities, cities, or towns. Hospitals are the most expensive setting of care and not an efficient use of health services.

This phase one report engaged stakeholders in an examination of the current state of Indigenous Palliative and End of Life Care in the South West LHIN utilizing applicable resources from the Lakehead University Improving End of Life in First Nation Communities research project. This report provides findings of the initial phase of the capacity development model for Indigenous Palliative Care Program Development (readiness assessment) including a plan of action/recommendations.

The report is organized by:

- Context for Action
- Health Infrastructure and Palliative Care Services
- Patient Experiences
- Discussion
- Plan of Action

**CONTEXT FOR ACTION**

Indigenous People living in First Nation and Aboriginal Communities in the South West LHIN lack access to culturally appropriate, quality palliative care services at home. A framework for developing palliative care for Indigenous people in First Nations and urban communities has been developed, which combined with health system transformative changes described below, prepares a path forward for more equitable health end of life health care for Indigenous people.

**Auditor General's Report on the State of Palliative Care in Ontario released December 9, 2014.** The audit of Palliative Care highlighted that the Ministry of Health and Long-Term Care needs to obtain more information on the services that are available, their costs, patients' needs for services and the mix of services which would best meet patient needs in a cost-effective way. This information is essential to the development of an integrated and co-ordinated system for the delivery of palliative care in Ontario. People in Ontario who have a similar need for public services expect to receive the same level of service regardless of where in Ontario they live. They also expect funding to service providers to be commensurate with the level of service being provided. However, the Auditor's Report found that this is not always the case.

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2 Lakehead University Recommendations to Improve Quality and Access to End of Life Care in First Nations Communities Dec 2014
Indigenous Hospice Palliative Care Planning | Readiness Assessment Report

Bringing Care Home, the March 2015 report of the Expert Group on Home and Community Care led by Dr Gail Donner, highlighted the ongoing service challenges in the home and community care sector. The current model is cumbersome, lacks standardizations and does not consistently deliver services that people need. However the Expert Panel encouraged the government to focus first on functional changes before addressing any structural changes.

Patients First: A Roadmap to Strengthen Home and Community Care, released May 2015 by the Ministry of Health and Long Term Care, outlined 10 initiatives as important steps toward transforming home and community care to ensure that clients and their families are at the centre of everything they do including bundled care initiatives, more nursing services at home among other activities. Providing greater choice for Palliative and End-Of-Life Care was one of these initiatives noting that many Ontarians want to stay in their homes as long as possible. Whether a patient wishes to receive end of life care at home or in a hospice, Ontarians deserve to choose the kind of care they want to receive. MOHLTC will support greater patient choice for palliative and end of life care. The report notes that MOHLTC will expand access and equity in the health system, establish clear oversight and accountability, and introduce new supports for caregivers. They will also support enhanced public education on the issue of advanced care planning so that families are aware of the wishes of their loved ones when it comes to palliative and end of life care.

In order to achieve the 10 initiatives outlined in the roadmap, and to ensure that high quality, timely and appropriate home and community care is available now and in the future, the government and their partners will be developing a rigorous capacity plan. This capacity plan will include targets for local communities as well as standards for access to home and community care and for the quality of client experience across the province.

Hospice Palliative Care Capacity Planning Draft Report for the South West LHIN (July, 2015). The South West LHIN is engaged in developing a Hospice Palliative Care Capacity Plan responsive to recently released reports on the state of palliative care in Ontario (Excellent Care for All Act; Bringing Care Home Report 2015). To this end, the South West Hospice Palliative Care Network Lead has undertaken numerous planning activities. The above-mentioned detailed report was released in July 2015 and provides service statistics on the numbers of supported deaths in various settings for the South West LHIN. They were unable to obtain any Aboriginal specific data.

The South West LHIN is interested in advancing an Aboriginal Perspective in Hospice Palliative Care Planning, utilizing the best practices from the five year Lakehead University project (described below) as the guidelines. The vision of the South West LHIN Hospice Palliative Care is to improve the Hospice Palliative Care experience for Indigenous People in the South West LHIN. A draft slide deck was presented to the Aboriginal Health Committee for the South West LHIN in January 2015 by Lisa Gardner, South West Hospice Palliative Care Network Lead and Vanessa Ambtman-Smith, Aboriginal Health Lead, South West LHIN regarding their vision. Investing in this initiative is to inform the Aboriginal Hospice Palliative Care Capacity Plan.

Lakehead University’s Centre for Education and Research on Aging and Health (CERAH) undertook a 5-year research project entitled “Improving End-of-Life Care in First Nations Communities” funded by the Canadian Institutes of Health Research (2010-2015) Released in December 2015, the outcome of the research was to document innovative practices and a community-led process for providing access to palliative care services in First Nation communities. A Framework to Guide Policy and Program
Development for Palliative Care in First Nations Communities has been developed and provides an integrated approach to addressing the gaps in palliative care services in First Nations communities. This research is a partnership involving four First Nations communities from Ontario and Manitoba: Naotkamiegwanning First Nation, Fort William First Nation, Six Nations of the Grand River Territory, and Peguis First Nation. The goal of this research was to improve the end of life care in First Nations communities by developing community-based palliative care programs and teams www.eolfn.lakeheadu.ca. This long awaited research has been well received from academia, health policy analysts and governments. More than 130 tools and policy papers emerged from this five year project. This paper has utilized the tools from Improving End of Life in First Nations project as expected.

Patients First: A Proposal to Strengthen Patient-Centred Health Care in Ontario released December 2017. While acknowledging that Ontario’s health care system has improved significantly, the next phase of the Ministry of Health and Long Term Care plan to put patients first, is to address structural issues that create inequities. Of particular interest to this project is the commitment to engage with First Nations, Metis and Inuit partners about how this process can complement ongoing work to strengthen health outcomes in Indigenous communities. The four components of system transformation include:

1. Effective Integration of Services and Greater Equity: Make LHINs responsible for all health service planning and performance; and identify sub-LHIN regions as the focal point for integrated service planning and delivery (note that these regions would not be an additional layer of bureaucracy).
2. Timely Access to, and Better Integration of, Primary Care: LHINs would take on responsibility for primary care planning and performance improvement, in partnership with local clinical leaders.
3. More Consistent and Accessible Home & Community Care: Direct responsibility for service management and delivery would be transferred from CCACs to the LHINs.
4. Stronger Links to Population & Public Health: Linkages between LHINs and public health units would be formalized.

Palliative and End-of-Life Care Provincial Roundtable Report. A report from the Parliamentary Assistant John Fraser to the Minister of Health and Long-Term Care; March 2016. On March 11, 2015, The Ministry of Health and Long Term Care announced a $75 million investment over three years to provide patients with more options and access to palliative and end of life care. Coinciding with the release of the Fraser Roundtable Report, the investment would improve community-based hospice and palliative care services including:

- Supporting up to 20 new hospices across Ontario and increasing the funding for existing facilities.
- Increasing supports for caregivers that will help families and loved ones support palliative patients at home and in the community.
- Promoting advance care planning so that families and health care providers understand patients’ wishes for end of life care.
- Establishing the Ontario Palliative Care Network, a new body to advance patient-centred care and develop provincial standards to strengthen services.
The report noted that the Ministry shares the common goal of improving health outcomes for Indigenous people in Ontario. It includes a section articulating how First Nations, Métis and urban Aboriginal perspectives are not captured or reflected in palliative and end of life services. Examples include, not receiving the support they need where they feel culturally safe and respected, and the need for Indigenous people to have more access to long-term care supports from trained, culturally competent staff. Indigenous partners spoke about the challenges that families experience when few health care providers offer culturally appropriate palliative care and few organizations accommodate traditional practices.

*Bringing Order to Indigenous Primary Health Care Planning and Delivery in Ontario, AHACs and Aboriginal CHCs Response to Patients First: A Proposal to Strengthen Patient-Centred Heath Care in Ontario released March 2016.* The Aboriginal Health Access Center (AHAC) / Aboriginal Community Health Centres (CHC) Leadership Circle, representing ten AHACs and three Aboriginal CHCs, were invited to respond to the *Patient’s First* (2015) report. It provided an overview of the AHAC model including leading practices and innovations across from the province from AHACs and Aboriginal CHCs. The response noted systemic impediments and barriers to the AHACs / Aboriginal CHCs progress remain and provided 22 recommendations to address key issues. The AHAC and Aboriginal CHC leadership grouped these recommendations into four proposals: More effective integration of services and greater equity; timely access to primary care, and seamless links between primary care and other services; more consistent and accessible home and community care; stronger links between public health and other health services.

*The AHAC and Aboriginal CHCs Response* specified that Home and Community Care continued to be an area of Ontario’s health system where Indigenous people are at great risk and come into regular harm. There continues to be significant confusion amongst service providers, jurisdictional discord, systemic racism and inequities that are causing undue patient, family and community stress at best and premature death and dying at worse. A key success inside the system is AHAC leadership and management of home and community care coordination and services including palliative and end of life care.

The recommendations specific to palliative care are:

1. That the AHACS have extended mandate and service-provision scope, including care coordination, hospital discharge, home and community care services, and palliative / end of life care.
2. That CCAC Care Coordinators working with Indigenous populations come under AHAC and Aboriginal CHC management where possible.
HEALTH INFRASTRUCTURE AND PALLIATIVE CARE SERVICES

Primary care is the foundation of the healthcare system from which people receive most of their health care services. The following section outlines the health infrastructure in the South West LHIN catchment area specific to palliative care services and more particularly should be available to Indigenous citizens residing in the area. While these service providers are available, it should be noted that the burden remains on the shoulders of informal caregivers for palliative care. Many individuals are faced with stark choices as they try to balance the need to provide for their family while caring for a terminally ill family member.

First Nations

There are six First Nations in the South West Local Health Integration Network catchment area, which include: Chippewas of the Thames First Nation; Chippewas of Nawash Unceded First Nation; Munsee-Delaware Nation; Oneida Nation of the Thames; Saugeen First Nation; and Caldwell First Nation.

At any given point there will be an active caseload of 35-60 home and community care clients in each of the First Nations. Furthermore, the number of complex palliative care clients ranges from 1-2 per month for each community.

The infrastructure for the Home and Community Care program may vary by First Nation but usually consists of a full and/or part time Registered Nurse (RN), or Registered Practical Nurse (RPN) and Personal Support Workers (PSWs) funded by First Nations and Inuit Health Branch, Health Canada. These are federal employees. The FNIHB-funded salaries are not usually competitive with provincial wages, which poses challenges with human resources recruitment and retention. A limitation of the federally funded Home and Community Care program is that palliative care is not an essential service element. Furthermore the FNIHB program operates between the hours of 9 a.m. and 5 p.m., Monday to Friday, which does not provide nursing or PSW services for palliative clients afterhours on evenings or weekends when the need is often highest (FNIHB Program Compendium, 2011/12). All of the abovementioned First Nations have a Home and Community Care program funded by FNIHB except for Munsee-Delaware Nation.

A powerpoint presentation was prepared in 2014 following discussions by the South West LHIN, South West CCAC and area First Nations/Aboriginal organizations. Their objective was to develop a better understanding of what health services First Nations/Aboriginal communities are accessing, who the programs are serving and how the South West Community Care Access Centre (CCAC) work alongside these services. The types of services identified in the report as currently provided by the CCAC may include nursing, case management, specialized services (e.g. OT/PT). The type and level of services provided vary significantly by community.

A jurisdictional barrier results from palliative care not being a funded service under the federal (FNIHB) Home and Community Care program while the provincial/territorial home care services do not consistently extend into First Nations communities. The CCAC is responsible for providing PSWs according to their mandate, yet often do not provide PSWs on-reserve as they view it as a duplication of services with the FNIHB PSWs (whose program operates during business hours whereas CCAC provides after hours care). Due to lack of home care services, First Nations people lack the choice to
die at home if that is their wish. Most First Nations people die in urban areas, in hospital or long-term care homes, separated from family, community, and culture.

A common gap in service identified by the First Nations in the report was the lack of joint discharge planning, meaning there is not contact between the CCAC and the First Nation Home and Community Care program. Improvements in discharge planning would reduce the time between when the client’s needs were identified and services put in place. Some of the issues included how communications occurred with the First Nation clients, ensuring the clients have supplies or services lined up as well as the necessary follow-up and/or supports. The overall goal is the provision of culturally safe health care. Another gap in service for complex palliative care clients was transportation.

Southwest Ontario Aboriginal Health Access Centre

Fully accredited through the Canadian Centre for Accreditation (CCA), the Southwest Ontario Aboriginal Health Access Centre (SOAHAC) is an Indigenous community-governed, primary health care agency that blends western and Indigenous healing approaches. SOAHAC has 70 staff serving 35,000 Indigenous people in 13 communities along the London-Windsor corridor and into the Grey Bruce, Owen Sound areas of the province. SOAHAC is status blind[^3], and operates four primary health care sites: London, Chippewas of the Thames First Nation, Owen Sound and Windsor, and outreach clinics to four rural, southern First Nation communities.

Part of SOAHAC’s integrated care model means that SOAHAC health providers work as a team, to ensure that clients have access to the right services when they need them. SOAHAC’s integrated care teams consists of Doctors and Nurse Practitioners, Traditional Healers and Elders, Dietitians, Child and Youth Workers, Mental Health and Addictions Counselors, Social Workers, Nurses, Support Staff and more. The service model promotes an Indigenous cultural worldview of interconnectedness and the balancing of the physical, mental, emotional and spiritual aspects of wellbeing. Everything SOAHAC offers is rooted in its wholistic, integrated approach to health and wellness. All services and aspects of service delivery relate to the life cycle, and relationship with everything within Creation – culture and empowerment, self, family/Clan, community, nation, and the universe.

A variety of outreach services are provided on location in the First Nation communities and within Friendship Centres.

- Onyot’a:ka (Oneida Nation of The Thames)
- Deshkan-Zibiing (Chippewas of The Thames First Nation)
- Munsee-Delware First Nation
- Aamjiwnaang (Chippewas of Sarnia First Nation)
- Delaware Nation at Moraviantown
- Caldwell First Nation
- Bkejwanong (Walpole Island First Nation)
- Can-Am Indian Friendship Centre, Windsor
- Zaagiing (Saugeen First Nation)
- Neyaashiinigmiing (Chippewas of Nawash First Nation)

[^3]: Means the organization is inclusive and serves all self-identified, First Nation, Inuit, and Métis (FNIM) people, both status and non-status, living on and off-reserve and in rural and urban settings.
• N’Amerind Friendship Centre, London
• M’Wikwedong Native Cultural Resource Centre (Indigenous Friendship Centre), Owen Sound

Supporting Aboriginal Seniors at Home (SASH) Program

The SASH team works with urban and on-reserve First Nations, Métis and Inuit Seniors aged 55 and over. The program goal is to improve access to culturally appropriate primary health care services and to help manage or prevent chronic conditions. The SASH team helps people to live safely in their home for as long as possible by offering the following services:

• Aboriginal Patient Navigator helps clients find their way through the complex hospital care system by identifying barriers to care, helping understand and complete forms, and linking with other services like follow-up appointments or Traditional Aboriginal Healers.
• Nurse Practitioner (London and Chippewa) provide primary care services in the clinic or in the home setting. An NP promotes good health and helps maintain a healthy lifestyle by performing physical check-ups, providing education and information, diagnosing and treating illnesses and injuries, and more.
• Senior’s Health Advocate (London and Owen Sound) or Traditional Healing Coordinator (Owen Sound)
  - In the London area, the Senior’s Health Advocate advocates on behalf of the client to make sure appropriate contemporary and Traditional health care services are in place. They help to access community and social services, and to develop a health care plan.
  - Similarly, in Owen Sound, the Traditional Healing Coordinator ensures access to culturally safe care and increased familiarity with cultural and Traditional knowledge and Indigenous perspectives.

Oneida Long Term Care Facility

Oneida Long Term Care Facility is located in Southwold on the Oneida of the Thames First Nation. It opened on February 1, 2012 as a Class A facility with 64 beds. It is overseen by the TSI’Nu:YoYaTNaTuHuwaTsni Board of Directors and is an unincorporated association that is at arm’s length from the Council. With over 100 employees (many of whom are First Nations employees) the centre’s staff includes nurses, personal support workers, activity aids, contracted physiotherapists and occupational therapists, social workers and a foot care nurse.

The facility provides services primarily to residents of Oneida of the Thames although it is inclusive and accepts referrals from any other First Nation. The turtle, bear and wolf are reflected in the structure of the building; the welcoming lobby with the huge overhead dome represents the turtle shell, and on top of that is the tree and makes a peaceful place for residents to sit. The Wolf Den is located beyond that large space, where there is entertainment, crafts activities, bingo, traditional ceremonies and church services.

There are no short term beds and palliative care is provided to residents already residing in the home. The facility is designed for elderly people with dementia and there is no focused care for schizophrenia; specialized care for these patients must be provided in a more appropriate setting. Utilization rates for beds must be maintained at 98-99% in order to secure funding.
Admission to the home is through the South West CCAC in consultation with the family physician. Members of the CCAC team visit the hospitals to identify those who would like to be considered for care at the Oneida Long Term Care Facility. CCAC categorizes these patients as; crisis is categorized as 1, Oneida First Nation as 3, any other First Nation as 4. Oneida First Nation community members are given priority, unless there is a category 1 from TCHC.

Upon notification by the Oneida Long Term Care Facility to CCAC that there is a vacant room, CCAC review their waiting list and in consultation with the care facility agree on a suitable resident. That person has 24 hours in which to decide whether they wish to take up the offer. During this time the room is thoroughly re-painted and refurbished and is ready for the next individual, usually within 3-4 days.

The CCAC Coordinator assessment is reviewed by staff prior to the resident arriving at the facility so there is a thorough understanding of that individual. The standard assessment is carried out 6 weeks after admission then occurs annually. If there are significant changes, such as becoming palliative, an Urgent Care conference is arranged where every effort is made to include the visiting doctor if possible. New residents along with their families are welcomed into the home by the nurse and families are welcome to stay for the first 24 hours to facilitate the transition.

If a private bed has been vacated and there are no private patients in the system, that bed could be switched back to basic to continue the movement and to honor the duty of the facility to assist hospitals free their beds of long term care patients. There is an understanding with this facility and the community that Oneida residents are not impacted by the lack of basic beds as opposed to private. Utilization rates affect funding, which leads to reduction in staff which impacts the residents in a very negative way.

Residents are encouraged to remain at the facility once their condition reaches the palliative state. Families are welcome to stay 24 hours a day and are able to have contact with the nurse and Personal Support Worker during this time. Lounge chairs, recliners or a cot in the room are provided for the comfort of the family together with supplies of snacks, tea and coffee. An Elder or Minister is available if required.

As the resident begins the path of palliative care, a case conference is usually held where the family is invited to attend. The Care Conference allows an opportunity for everyone to be aware of the current status of the individual, the physician thoughts on the patient’s condition, discuss an active resuscitate plan (or nature death) and how the palliative care will unfold. Following this case conference if there is a need for PT/OT or social worker, this referral is made immediately.

If necessary, an urgent care conference is organized bringing together as many people as possible. The purpose of the conference is to address any immediate needs then touch base with family. Sometimes the family will bring forward any concerns which are either handled one-on-one or as a team depending upon circumstances. Sometimes mini-conferences are held with the nurse, administrator and may include others such as the pharmacist; these are sometimes initiated by the family if clarification is required and are on an as needed basis.

Occupational Therapy, Physiotherapy and foot care are provided through contracted services. The service provider has high standards of practice, are responsive and culturally competent from the perspective of understanding First Nations.
On passing of a resident there is a special ceremony taught by the elders in this community. The room is sprayed with cedar and tobacco going in a sunrise to sunset direction, to release any spirit in that room.

South West Community Care Access Centre

South West CCAC partners with 19 hospital corporations, 60 community support agencies, 77 long-term care homes, 19 Family Health Teams and 12 service provider agencies to deliver services to more than 53,000 clients annually – including those who wish to die at home. The South West CCAC provides end of life clients with a robust service plan, which can include nursing visits, therapies and personal care. During the last 20-30 days of life palliative clients experience increased pain and limited mobility. Families caring for a dying relative need support to help prevent caregiver burnout and to assist palliative clients to experience a peaceful death at home.

The Client Brochure indicates range of services offered by the South West CCAC include:

- Care coordination
- Nursing care including wound and ostomy care, IV therapy, medical monitoring, help organizing medications, and specialized care for people at the end of life, provided by Registered Nurses and Nurse Practitioners
- Personal support to help with day-to-day activities
- Therapy and support to help you feel better and do more, including physiotherapy, occupational therapy, speech-language therapy and nutritional counselling
- Social work, for practical and emotional support during difficult times
- Medical supplies and short-term help with equipment
- Connections to community support services such as meal delivery and dining programs, transportation, exercise and recreational programs, Adult Day Programs, and homemaking
- Connections to primary care, including help to find a family doctor
- Connections to rehabilitation, complex continuing care, assisted living and supportive housing facilities, and long-term care homes
- Support for children with disabilities and children and youth with mental health and addiction challenges.

The South West CCAC is responsible for the coordination of care of clients requiring palliative care in the South West LHIN. The cohort of clients that receive the majority of palliative care services are those defined by the South West CCAC as being Complex Palliative (CP). The South West CCAC supported a total of 879 deaths at home in 2013/14 across all populations, of which 563 were Complex Palliative client deaths. For these clients, the top three services accessed from the CCAC were visiting nursing, combined homemaking and Occupational Therapy (Jenkyn, McQueen and Gardner, 2015).

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The Palliative Care e-Shift (e-Shift) program is a model of care that allows for personal support workers (PSWs) connected virtually to nurses through Smartphone technology, to provide palliative clients the end of life care they need. The South West CCAC, with support from the South West LHIN, are the coordinators of care for the e-Shift model. South West CCAC organized the e-Shift program in conjunction with hospitals, long-term care homes, community organizations and community partners. E-Shift seeks to improve palliative clients’ quality of life during the final days of their life, reduce hospital and emergency visits and decrease caregiver burden.

In many rural communities it is often difficult to arrange for nurses, who provide specialized overnight assistance to families of palliative clients. This nursing shortage resulted in more frequent use of hospital resources to support home care palliative clients at the end of their life and a limited ability to support clients to die in their location of choice. The new e-Shift model of nursing care was introduced to meet the needs of home care clients who want to die at home with their families. E-shift involves specially trained PSWs receiving support from an off-site nurse through a Smartphone application. The PSW carries out activities on behalf of the nurse while providing overnight care for palliative clients. Family members are then able to get much needed rest at night, so they can be ready to care for their relatives throughout the day.

Hospitals

There are currently 19 public hospitals (32 sites) and 1 private hospital in the South West LHIN. Part of the focus of the LHIN’s Blueprint is to optimize hospital-based resources in order to build capacity and access to quality treatment and care throughout the LHIN.

In the Hospice Palliative Care Capacity Planning in the South West LHIN Report, Jenkyn, McQueen and Gardner (2015) found “that individuals receiving acute care bedded services may also receive different palliative services (i.e. palliative physician/NP consult) and a number of hospitals may also have dedicated “palliative beds” with varying level of supports. Inconsistency of palliative services for acute bedded patients has been identified as a gap.” Participants in this report were unable to identify if appropriate space for traditional practices such as smudging or cedar baths were provided at these palliative beds.

Long Term Care Homes

In the South West LHIN, there are 79 Long-Term Care (LTC) Homes with a total of 7,428 beds. LTC homes are subsidized facilities that provide nursing and personal care to individuals who are no longer able to live independently in the community. Many LTC homes also offer short term respite care. LTC homes are also known as homes for the aged or nursing homes.

Residential Hospices

Residential Hospices are alternative home-like environment for individuals who do not wish to die at home or in hospital. The community-run hospices provide 24-hour care for patients and their families who are dealing with a terminal illness; this care aims to provide for physical, psychological, emotional, social, spiritual and practical end of life care and support. Patients are able to die with dignity in a
home-like setting. The usual length of stay is less than 3 months with the care provided by a team of professionals and volunteers.

As of July 2015, there were three Residential Hospices in the South West LHIN catchment area:

1. **Sakura House**

Sakura House has 10 private patient rooms in a 12,000 sq ft home located in Oxford County just east of Woodstock. The hospice opened in 2009 after a nine-year planning period. Sakura is the Japanese word for “cherry blossom”, symbolizing an annual spring celebration of the shifting seasons. The hospice offers 24/7 care and is operated by the VON.

2. **Residential Hospice of Grey Bruce**

Residential Hospice of Grey Bruce is a 6 bed facility located in Grey County. It opened in 2013 and is currently in the planning and fundraising stages of building a new facility, which will be named Chapman House. It is a community-run hospice with a multidisciplinary team that offers an alternative for those who do not wish to die at home or in the hospital.

3. **St. Joseph’s Hospice of London**

St. Joseph’s Hospice of London is a 10 bed residential care program located in London-Middlesex County. It is a faith-based organization whose services are offered at no cost and are available irrespective of age, gender, religion, race, ethnicity or economic status. This facility opened in January 2014 under the new ownership of the St. Joseph’s Health Care Society.

**Aboriginal Patient Navigators (Cancer Care Ontario and SOAHAC)**

Cancer Care Ontario, under the Ministry of Health and Long Term Care, has appointed Aboriginal Cancer Leads and Aboriginal Patient Navigators in all regional cancer programs to offer individualized assistance to help residents overcome healthcare system barriers and facilitate timely access to care for First Nation, Inuit & Métis (FNIM) patients and families.

The Aboriginal Patient Navigator attached to the South West Regional Cancer Program liaises with and advocates for the needs of First Nation, Inuit & Métis patients with cancer and their families. They work to improve access to cancer services, while addressing cultural and spiritual needs. An aspect of this role is the facilitation and coordination of access to cancer services both in the hospital and community, including networking with health care providers and with the patient. As noted earlier in this report, SOAHAC also employs an Aboriginal Patient Navigator.
South West LHIN Aboriginal Health Committee

This advisory committee to the South West LHIN meets bimonthly and is composed of Indigenous communities and health service providers. Topics of discussion include (but are not limited to):

- Health needs and priorities within Aboriginal Communities (First Nation, Métis, Urban and Rural).
- Opportunities for the integration and coordination of health care services where applicable.
- Opportunities for alignment with existing Aboriginal/First Nation/ Métis regional, provincial and federal health planning structures to improve health outcomes.
- Opportunities for alignment with existing mainstream health programs and services determined by Aboriginal community and/or Aboriginal Health Service Providers (HSPs).
- Targeted engagements with specific Aboriginal populations as it pertains to the work of the South West LHIN and the needs of those populations.

WHAT WE HEARD

Expanding Equitable Access to Services

Palliative care services are not equally accessible to Indigenous peoples, particularly on reserve. There are a variety of ways that palliative services are restricted for Indigenous peoples. One of the most startlingly discriminatory practices of the current system of palliative care services is that access can be based on whether or not the patient has a working phone. Every participant in this research spoke about the issues facing Indigenous peoples, both on and off reserve, when they did not possess a phone. In many instances, the patient did possess a phone but could not afford the cost of minutes. The CCAC, in particular, requires a phone number in order to ensure they can contact the patient. This practice automatically discriminates against those with lower income. Participants shared extraordinary efforts they made to ensure that a client had a phone and could answer it to receive CCAC services. An alternative must be established, as access to services is a Constitutional right. Participants stated,

“...if a CCAC referral is made or a referral to our team and the person doesn't have a reliable way to be contacted...a phone with minutes, daytime hours, those kinds of things, then things can go terribly wrong because they are not reached and the file is potentially closed which does happen. Say for example I did a referral, I thought the patient had a phone or the primary care provider didn't think to ask that, and all of a sudden CCAC try to get hold of them and cannot reach them because the phone number they have is out of services so things go terribly wrong there.”

“...the visiting nurse will try to set up saying she will be at that day at that time, but for the people with CCAC service, they are required to have a phone call interview before receiving services, so if I refer, CCAC needs to ask if the client knows and they ask for a phone number...that can be a major challenge. Another challenge we have is that texting is a lot cheaper than calling. Texting with our clients is something that is not encouraged because if I have my work phone with me, and say I'm off sick, I might not check it...also if it is turned off, we might not get that information; and you can't text the office and if I text the person, we don't necessarily know if the phone is on or off. The trouble is it is so much cheaper to text rather than call.”
The worst case scenario can be devastating. One person shared, 

“Where things go wrong and what happened in another case...was when a patient was discharged and the person didn’t have a family doctor and no phone/primary care; the patient was discharged home with template type of care plan and no supports in place. They just passed away and were found by a family member.”

Additionally, the E-shift services provided by CCAC, which are personal support workers connected to off-site nurses in the last few days of life, can only be accessed where there is cell service. Though this is an innovative program that allows overnight coverage at end of life and supports a person's choice to die at home, it is dependent upon the presence of technology. The e-Shift PSW service is only provided to clients who have internet in their home; however the First Nations identified that many end of life clients do not have internet, thus they cannot access this service. For Aboriginal communities near urban centres, this would not be an issue, however, there are those communities who still do not have reliable access and cannot benefit from this service.

Transportation to appointments was consistently mentioned by participants as an issue of access to services. Patients are required to travel to attend palliative appointments which present a major barrier to care. Service providers make assumptions that if there is a vehicle outside of a patient’s house, then that person is insured, or able, to drive. This assumption discriminates against those who have lower income or are unable to drive. In urban areas, physical limitations may make transit too difficult or impossible. Participants shared,

“...we are only 45 minutes outside London, but transportation is a major issue all the time...there are a lot of palliative treatments at the London Hospital that palliative patients would benefit from, that would be great.”

“...the CCAC’s misconception was that just because a car was in the laneway on-reserve, that it was licensed to drive and is insured. Or that the car even works, which is a brutal assumption that should not be made”.

“I would ask for a full time driver...and a vehicle. Only because I know we’ve had to call just to get clarification on AIAl on the medi-trans on reserve and off reserve. It’s strictly on-reserve. People in the city of London have no contribution agreement for transportation. That’s a big discrimination between on- and off-reserve.”

Many participants shared that they were concerned that the onus is placed upon the patient to attend appointments for care, which then forces individuals with health issues into dangerous driving situations. Though they may still have a valid licence and access to a vehicle, individuals with sight issues, for instance, should not feel as though driving to an appointment by themselves is the only way to access care.
Another frequently mentioned barrier to access services is the assumption of existing supports. If CCAC believes that there is nearby family or other agencies that can share the responsibility of palliative care, personal support workers are denied. Participants stated,

“Once they found out there was other family, they would deny PSW services. PSW was one of the things that was needed the most. Because they had family living in London, they would be denied. They don’t understand the dysfunction of families. Yes I might have a brother in the next room but I can’t rely on him to look after me.”

“...if that potential support isn’t drawn into the equation, the assumption is made that the person has better support than they do because a lot of CCAC’s mandate is to rely on supports people already have then fill the gaps. I can see examples where someone is discharged home palliative and then SOAHAC will take care of them so the mainstream supports are not put in place so they didn’t get PSWs and some of the other supports which they needed and were eligible for.”

It is apparent from this research that access to palliative care for Aboriginal peoples is unequal between urban and on-reserve communities. Participants were clear that on-reserve community members receive a lower standard of care because of their location. Access to services from CCAC is denied after 5 o’clock in the evening if the patients are on reserve. This discrimination means that First Nation communities must do what they can, with very little resources, to support their community members. Almost every participant in this research mentioned the challenges that are faced when services are denied. One participant stated,

“I had an elderly client and the hospital forced her out but she needed PSWs...we needed their resources so they sent them out. But something happened... the lady lived at the end of a long road and a car came down pulled into her driveway and then drove away again. The worker in the house was so scared that she called the agency and they pulled all the PSWs out and they wouldn’t go out to the reserve anymore as they were frightened of break-ins. The family had to kick in after that and be there at night time because agencies pulled PSWs out...at the very beginning the agency said they would not go after 5pm.”

Much of this discrimination is blatant ignorance of reserves and Indigenous peoples. However, those that are in management positions do have the responsibility of ensuring the safety of their staff. This is a responsibility that should not be dependent upon geography, but considered with every location to which workers are dispatched. Fear of reserves and Indigenous peoples is not an excuse to deny services. One person shared,

“Flat out saying it: We flipped to VON when we needed to put E-shift in and some staff are not comfortable going to work on the First Nation communities. I did have one situation where I didn’t feel it was safe for staff to go in there, so I didn’t even offer up the enhanced support. It was just a situation in the house - the lady didn’t have door locks on the door even, in a remote area, and her family was risky and known substance users. Having a client, a PSW and all those narcotics - it made me nervous. Unfortunately I didn’t feel it right to offer her the extra support.”
Many times, participants stated it was a mixture of circumstances that routinely led to the prevention of home palliative care on reserve. One person stated,

“It is interesting our ability to deploy resources is different than if I were in London. I had someone on the weekend that I saw for the first time last week. She was fine when I saw her in the week and expected she would change so I put in all the resources I hadn't got in yet... nurses, but didn't setup. She deteriorated at night and called CCAC who got a nurse in...she was in the city where there's a difference and there shouldn't be. They got through the night and called me...but why should this CCAC client get something another CCAC client doesn't...it is lack of nursing sometimes. Medication was a challenge sometimes having narcotics in the house with other people. She got a pump and there were issues. When it came to end of life care, it was obvious they couldn't manage at home so we struggled because she wanted to stay in the community, but because of the pump it was a challenge so she ended up in the nursing home...”

More Health Care Providers Should be Knowledgeable About Palliative Care

A significant barrier to care mentioned by participants was palliative care training. It is apparent that though some nurses have a degree of palliative training, many other participants in the circle of palliative care, including personal support workers, do not. It was pointed out by one person that the palliative care training that has been received has not been updated. One participant stated,

“...their nurses have had some palliative training. With First Nations the PSWs are typically provided through their community - they don't have training specific to palliative care. If we get into a situation of the E-shift program, those PSWs have additional training including palliative care. Other therapies (OT/PT) don't have training specific to palliative care.”

More Flexible Service Models with Additional Human Resources

Another barrier to palliative care is the lack of staff. Providing around the clock care to a palliative care patient in their home requires a number of trained staff to provide support. One person shared,

“...sometimes we just don't have the manpower. I know there was an issue recently about a client who didn't get the E-shift supports they needed and the feedback was that the client’s family felt they were denied the services because they were on a First Nation. That had nothing to do with it as all across the area, including First Nations, we didn't have enough trained workers in palliative care in the region. We were unable to provide enough services for a lot of people that week because we didn't have the staff. I do know it's happened twice - it had nothing to do with them being First Nations - it had to do with we were short staffed right across the board. There could be 15 people actively dying today, and tomorrow it could be 20, so it's very unpredictable.”

The First Nation Home and Community Care workers frequently pick up the slack when services are not provided by the CCAC. Many participants shared that there was an expectation that this would occur, especially upon discharge of an on-reserve patient from hospital, and yet First Nation communities do not have funding for these services either. One person stated,
“I had a gentleman who didn’t want anyone from the community to look after him in the home. At one point he wanted to stay in hospital but the hospital really wanted him to come home so I said to them if you want him to come home then you provide the care, I don’t have the funding to provide care, so they did and they put in three PSWs which worked well, but I had to force the issue.”

One of the key players in the circle of palliative care are personal support workers. However, they are difficult to recruit and retain. First Nation communities receive funding from First Nation and Inuit Health Branch for a Home and Community Care program that is composed primarily of nursing services and some personal support workers services. These workers are federal employees and the program has been capped at 2% enhancements for many decades and the participants noted funding is insufficient to meet existing needs. As such First Nations cannot provide competitive salaries (usually $12/hour) and the hours are rarely full-time for PSWs. PSWs provide support to the HCC clients, usually seniors already on the First Nation caseload. FNIHB does not fund palliative care services as an essential service. First Nations want additional funding from the South West LHIN to support more PSWs and enhance wages of existing workers. One person said,

“Oneida First Nation has a Long Term Care facility…it’s wonderful, people can stay in their own community, but what it means is that PSWs make more money in LTC so it’s hard for us to recruit and retain workers…I found this myself…it’s very different working in an institution versus working in community. In community, you need to have a certain amount of independence and be confident enough to be able to deal with what you are doing, or be confident enough to pick up the phone and call. Community work can be very isolated, and not everyone is comfortable with that but if you work an 8 hour shift in a care facility, regular hours and more money.”

Receive Palliative Care as Early as Possible

A significant barrier to care for Indigenous peoples seeking to pass away at home lies in the diagnostic process as being identified as palliative. Throughout the research, participants identified the issues with palliative diagnosis and the impact that this has on palliative care. The current diagnostic process encourages a relatively last minute approach, wherein relationships cannot be built nor do families and patients have time to understand what is happening. If potential patients do not achieve a particular percentage on an existing palliative test, they do not qualify for any services. Participants stated,

“I found a consult note during an ER visit saying ‘this person needs to be assessed for palliative care.’ That’s the only way to get the assessment. Needs a certain percentage scored on the PPS...this isn’t client-centred care, that’s CCAC-centred care. He wanted to die at home. I made the referral, did everything in my power to do so and it didn’t happen. All they would do is a weekly assessment and he didn’t even last the one week.”

“I think that’s why things didn’t turn out as well because we are not getting them in the palliative and tracking them - we’re getting the end of life. Study shows if CCAC is put in early, they do better - less ER visits, patients get used to them, can access, have a navigator. Then if things start changing, resources can be put in, but if you’re not connected, or don’t feel connected, that’s why you end in ER...which is why 60% came in - if people got CCAC at that number, they did a lot better.”

In addition to this, Indigenous patients are not always identified as Indigenous in the hospital. If they do not self-identify immediately, they may miss out on access to services, such as the Aboriginal
Patient Navigator. The hospitals are trying to make brochures and information readily available for Indigenous patients; however, they cannot make assumptions. One participant shared,

“Another thing that’s a big piece is that I know the intention of the SOAHAC Patient Navigators was to help people understand what they’re being offered and told, but a big piece that hampers that is the privacy legislation…the hospital cannot identify them as a First Nation person. How do they become aware that there is a person who can help them through the system? I had a client yesterday with upcoming surgery, he didn't know about the navigator to help him at the hospital and how does going home work and who to speak to. It’s about approach, the Aboriginal Patient Navigator is from this Nation so she has the cultural piece and they would be more open to asking her to explain rather than approach someone in hospital. We sometimes forget to check in to make sure people know.”

The current palliative process is a significant barrier that has emerged from this research. One participant sums up some of the barriers in one statement,

“The things that have stood out...is that early identification of Aboriginal would that make a difference? Second is early identification in the disease trajectory, so we’re putting in services or resources early enough. Third is difference in resources between urban versus non-urban. Fourth is physician care; often if you don't have a quarterback who's a physician - who is having the conversation about Advance Care Planning? Other health issues Aboriginal people have; maybe they're dying in hospital but we're not having the conversations. I think it will be way more important with the Aboriginal [community] because they have longer and more established relationships. How do you service the communities, especially the rural? To engage them with a Home Base Physician makes all the difference. Sometimes I wonder what I’m doing at the hospital because they do better at the home. As long as they’re getting treatment, that's important, but once they're end of life, it's a ‘home based team' that will keep them out of the hospital and not anyone else. Home based teams can be very different based on the community; we need to identify that for our community. I think engaging with the Aboriginal Primary Care Provider [SOAHAC and the First Nations] will be an important one.”

Support for Advance Care Planning

Project participants pointed out that Indigenous palliative care individuals and their families are not very familiar with Advanced Care Planning. These are conversations which can occur with primary care providers and family members in order to create a plan that can be utilized when an individual is no longer able to make decisions on their own. Unfortunately, these conversations rarely occur and palliative care is something that happens at the last minute. The reality of the situation, the complexity of the system and the emotions involved can be overwhelming. Participants stated,

“...if a client is coming home the family will tell me they are coming home. The service providers do not explain in lay language so they are often confused and don't know who has been to see them... was it OT or was it someone else; they are very confused about the whole process. We do have an Aboriginal Patient Navigator...who tries to help with discharges and we have so many people in and out of hospital and she only works by referral...there are times when we are in the loop but more times we are not.”
“I think where it’s going to be important is some point before, discussion take place on the culturally based team on how that looks for you, what do you want as you go to the end part of this journey, what supports are there for the family. In some cases it can be practical stuff...you’re in your home, you have all this stuff that is upsetting to look at, you don’t know what to do, you don’t even own a car, you’re 78 yourself. One of our team can go and help you sort through the stuff and throw out what you don’t need. There is no formal system or practical help right now for that.”

The conversations involved around palliative care are difficult to have, not only because of the information that needs to be communicated but because not every person is ready to accept it. This is complicated by the fact that there is a lack of information around palliative care and available services for Aboriginal peoples both on and off reserve. Participants shared,

“With the last elders that died, the families were not ready to say they are dying, they wanted them fixed and to come back. They were not ready and had not planned for a death.”

“They don’t have all the appropriate information. I have clients who don’t want to burden their family and if they knew there was someone there to help their families, they would die at home. In the hospital our people are taken advantage of – they need a navigator there to guide them and take any care they can get.”

“Yes, they are scared and it is not happening to me I’m staying at home and they expect that we will take care of them and don’t realize that we don’t have services for them, so it’s a lack of being informed.”

Families and Caregivers Find the Healthcare System Difficult to Navigate

Palliative care is a challenging experience to navigate for individuals and their families. The process is difficult not only because of the variety of service care providers that can be involved but also because of the lack of familiarity of the family and individual with what needs to occur. The palliative care part of the journey is one that is mired in emotion and understanding the vast amounts of information that are suddenly necessary can be very intimidating.

The care providers that are part of the palliative process are clearly responsible for the physical care of their patients, yet they also have an equally important responsibility to communicate information to the patient. According to participants, this is frequently forgotten. True patient-centred palliative care ensures that the patient is involved and knowledgeable about the process. This sharing of information empowers the patient and alleviates fears. One participant stated,

“...the OT/PT comes from the visiting agency, Parameds...Our PSWs comment on the manner of how they come in...So much is about approach, about not about telling them but asking them and explaining why...if you can ask and explain what the reasoning is and then explain to the individual. One instance the PSW gave was, the OT/PT was in a room with a client and was talking over the clients head without including him in the conversation. I don't know how I would feel as a client... but am I invisible? The PSW spoke up right there and made a point on including the client. The OT/PT realized what they did, directed the conversation to him, as opposed to each other.”
It is imperative that palliative care providers understand that removing the patient from the process by not sharing information or involving them in their own care, is indicative of the systemic institutional abuse historically experienced by Aboriginal peoples. This ignorance occurs with health care workers in the home but also at medical appointments. Participants stated that the anticipation of being spoken at in terms they did not understand caused the patients a great deal of stress and made them less likely to attend appointments. One participant stated that patients would benefit from someone attending appointments with them. The participant said,

“I found when I got them to an appointment and went in with them - they were more at ease. There was a lot of anxiety with the appointment. They were more at ease knowing someone coming in with you. Knowing it’s a relief that they don’t have to navigate it by themselves.”

Improving Caregiver Supports

The presence, or absence, of family in the palliative care process can be a determining factor for good care. As stated previously, service care providers will take the presence of family, regardless of circumstances, as a reason to administer fewer services to the palliative individual. This is a stressful situation for the family and the family is usually unprepared. Though they may be involved in the initial care coordination conference, it is difficult for family members to truly understand what may be required of them to take care of their family member. In addition, many family members are facing their own issues which add a degree of complexity. Many participants shared the challenges of family realities as one person shared,

“I’ve heard many times over the years, ‘I can barely take care of myself. I can’t take care of my mom/dad/brother.’ A lot of them are struggling to live. A lot of them are having health issues at a younger age; most of the adult children have multiple health issues, on top of mental health or other issues. There are layers of problems.”

A degree of family stability does not ensure problem-free palliative care, as the requirements of care will take their toll. One participant stated,

“...maybe the family member was part of the care coordination conference in hospital and suggested that they were very involved, and then in reality day to day are not able to meet commitment, so the patient gets left and there is a big gap unless someone picks it up and highlights it...I think the idea is ensuring there is a follow up for family members which is integral to the discharge plan. I think it’s difficult too as sometimes there’s a certain pressure because you are sitting in a meeting with all kinds of professionals and they think they are involved but then reality hits in (that you have 3 kids and a full time job and you and your mother never got along anyway) and the person cannot cope, so that’s a gap that leads to unmet needs where people just have...just felt pressured to something which was unrealistic.”

The families also lack the information necessary to support the choice to die at home. The information that is shared is overwhelming and unfamiliar. When health issues arise, families will panic and call 911 rather than another support, as they do not know what to expect with the palliative process. Participants shared,
“I think just around the choice to die at home isn’t just giving a person the choice. It’s really making sure they understand that, what it looks like, when his breathing gets shallow and the process would not be to call 911. Call SOAHAC, the healer, the advocate etc. but not 911.”

“...where the family decided to dial 911, in some cases that is what they had to do as they were unable to process reality and had not thought it through well enough with not enough support and phone numbers available to them. To have a sheet with all crisis and support people contacts names and numbers...is not formalized in this journey. The client where it worked really well had this in place with the same staff assigned to them. CCAC tries to ensure some staff but not always... clients who need high levels of care need to be covered and additional costs would be involved with more full time people. Staff commitment would improve and when this team is in place it needs to be accessible with no bureaucracy and who is in place.”

The supports available to the families are integral to good palliative care. As stated before, palliative care tends to be a last minute occurrence and care coordination is done quickly and with little warning. The family is forced to adjust to a number of unfamiliar people, each with different jobs, entering the home and asking questions. One participant stated,

“I’m just another face in the home; I’ve been going into the home for five years to do a B12 injection... the mom is dying, and there’s an absolutely new agency, new face...that’s an awful time for it. Nurses work hard to foster those relationships...”

Communication / Relationship with Service Providers

Another theme continually mentioned by research participants was that of communication break down between service providers. The lack of a solid working relationship between the many providers involved in palliative care makes seamless palliative service delivery a challenge. Health care service delivery for Indigenous peoples, both on and off reserve, is often difficult because of jurisdictional challenges. Different service care providers can be confused about who provides what services and what services are funded. Unfortunately, this confusion encourages a lack of communication and means that Indigenous peoples have little control over services for their own community members. With the number of potential service providers involved in palliative care, Indigenous patients and communities are rarely empowered by the process. In fact, participants said that Indigenous patients who are palliative have minimal control, or say in their care, as they are overwhelmed and confused by the vast amounts of information and decisions that need to be made. The locus of control of palliative care for Aboriginal people, whether they are on or off reserve, resides with non-Aboriginal organizations that lack proper knowledge about Indigenous peoples. Participants believe that one way to ensure better palliative care for Indigenous peoples is to have Indigenous peoples drive the process. Participants stated,

“I think it is a huge problem in the urban or Aboriginal population with ownership and who is in control...I think that is where all our problems are happening as many times whoever is in charge at that time - Community health centers or SOAHAC - everyone thinks everyone else is doing something so in the end I think the patient loses out.”

“Another part is our role at SOAHAC. We don’t have everyone on reserve...not every patient... so it is a case of so many cooks in the kitchen that sometimes nothing gets done.”
The circle of care model is one that is used throughout different health care systems. Like the Medicine Wheel, the belief is that it takes many different individuals, with various strengths, to unite and provide the full spectrum of services to the palliative patient. In palliative care, physicians, nurses, home care workers, personal service workers, and physical therapists all play a vital role. Every participant expressed concern at the break down of the palliative circle of care for Indigenous patients. The lack of communication between these palliative service providers is concerning and has a negative impact upon the palliative care experience. Participant said,

“Communication is key...I would say that there should be in my opinion a routine expectation that CCAC has done an assessment in home or a hospital that they automatically send a communication to any primary care provider to say they have assessed your patient as being palliative, where do you fit in. In one case I did get exactly that information, but has not been a matter of course. So formalizing something around communication would be another thing.”

“CCAC never sends us anything, no case notes or reports, no communication...we only hear vaguely what the client remembers. If I go into the home and CCAC are there I ask for verbal update...Oneida HCC are also left in the dark. I work best with HCC to give them orders...we work in partnership. I know CCAC are there but I do not know what they provide. We hear nothing, the client dies and we never hear from them again and I don't know if there is follow up or counselling. If client dies they are done...there is no report nothing – zero. Originally we had case conference (when I was at London site) with mutual clients, and then it all faded away again. It is just odd; it is not a circle of care at all.”

“The biggest problem we have is that the hospital does not recognize us as being in the circle of care, so they call and ask us for information but they will not share any information. That leaves us out of the loop and we look like idiots when we don’t know that someone is dying. The thing that could help the most would be to get all health care services in same loop.”

One challenge that complicates the creation of a seamless circle of care is the consent form. This form can stand in the way of the sharing of information between health care workers about a palliative patient. This can make it difficult for every member of the circle of care to look after a palliative individual to the best of their abilities. One participant said,

“I have tried to establish an open door policy with the visiting nurses but they don’t really bother...they perhaps come in one day and just sit there and only a couple speak. We discuss the clients who have signed a consent form, the others we don’t. My two nurses (RPN & CC) go and do assessments every 3 months with these people if they have consented to speak to us, the doctor or dietician, but if they are non consent with CCAC - their nurses cannot speak to us.”

In the realm of palliative care, the physician also plays a crucial role. However, participants felt that not all physicians saw themselves as part of a circle of care. Relationships with physicians can be difficult, particularly in palliative care. Participants stated,

“Being an NP we don’t always get all the reports...originally when we first got licensed to provide consults for clients, the OHIP billing wouldn’t pay the consultant fee to write up a consult note and send it back to us, they would only get paid to send it a physician. That has all changed recently last year where they get to send a NP consult note; not every physician is on board. This new 'clinical
connects’ thing we have if we know we have a client in hospital, we can go in there and try and figure it out on our own. Unless you are a physician it is very difficult to get information from the hospital.”

“The other struggle we have is physician support; most of the clients are linked with the physician on the health centre on the First Nation. Those doctors aren’t always willing to support palliative care. Some clients with physician’s off-reserve are more proactive in supporting palliative care.”

It is not only with outside health care providers where communication breakdowns occur. First Nation communities, SOAHAC and local Friendship Centers need to strengthen, formalize and centralize their communication so that no Indigenous person falls through the cracks. One of the ways this can happen is to ensure that the Aboriginal Patient Navigator is a constant presence in the hospital and that they are closely connected to all of the Aboriginal communities and Friendship Centres. One participant stated,

“Sometimes there’s a breakdown between the First Nations and SOAHAC. There needs to be some line of better communication between SOAHAC, N’Amerind Friendship Centre, the First Nations and CCAC. For one, there’s not an office. I think the Aboriginal Patient Navigator needs to be in the hospital. There needs to be an office designated. The Aboriginal Patient Navigator just wanders around. That’s definitely the first breakdown - there’s not an office designated for Patient Navigator in the hospital. I think if there was, there would be better communication.”

Participants shared many instances where these communication breakdowns and lack of relationships had consequence for the patient. One participant shared,

“For example, we had a client who passed away...they came home from the hospital and passed away within 12 hours of being home....and a nurse was to go out to pronounce the death of the clients. We got a call from that agency that one of our nurses was to go out, but our nurses had not been trained to do pronouncements. It ended up a bad situation where the client was in their home all day, and in the end the police were there and the client was not pronounced until early evening. That was unacceptable and very disrespectful to the family in our perspective.”

The circle of care is a fundamental part of palliative care, yet current palliative experiences of Indigenous peoples show that it is not working. Creating a reliable circle of care across different agencies, jurisdictions and geographies can be challenging, particularly when agencies that are involved are unfamiliar with Indigenous peoples. This kind of relationship building takes time and effort. However, when participants were asked about ways to improve the palliative experience of Indigenous peoples, they continually returned to the importance of the circle of care. Participants stated,

“There is a lot of family conflict too, understanding of the issues of the individual dying...conflict over the will, or if there’s a lack of will, protections. If there were a team involved they could work out these things and cause less stress to family members. If there's an identified circle of care team with them at the end of life with the family, that would be a whole other opportunity looking at their care and wellness.”

“Helping them not feel alone and connected with services is the challenging part, so when they are not able to travel so much there is more demand on care givers to care for them and transport them that is where the support needs to happen. When there is not circle of care around them, it increases the isolation. We try to coordinate care but they can be backwards and forwards from hospital to
home and it can be demanding to try and coordinate their care and time consuming to make sure they have the care they need and it puts strain on family members. I hear a lot about family conflict and lack of understanding of the wishes of the person dying so there needs to be a circle of care around those patients at end of life.”

The key to good palliative care is relationships. The option to die at home, wherever home may be, can be done well but it depends upon a solid web of relationships between service providers, patients and families. When service providers, government funders, and families come together with the journey of the palliative patient in mind, a relatively seamless delivery of services is possible.

“The reliance on the mainstream is very high right now. I think where it works well is if there’s already established partnerships and relationships. Say for example that our team is already involved in some way and they know the person, already been working with them, they have been a support, trusted, reliable part of the circle of care. Then I think it goes very well because they can advocate for the Aboriginal piece, contact the healer for visits...some healers do home visits and visit in hospital. It’s not well coordinated as it only works if relationship is pre-existing. Where they go wrong is the opposite, where there’s no pre-existing relationship. Perhaps they are in the hospital sick and not doing well and the team providing care is focused on the immediate crisis or concern. There’re not really in the mindset of trying to figure out the resources in place, and that kind of thing or the family member is not perhaps part of the meeting.”

“Where it’s difficult is if the family hasn’t had an opportunity to establish those networks. Then it falls apart... If you get a call and a person is going to pass away within 24 hours how is anyone going to put in meaningful relationships in place. But if they had good relationships already in place, but you would have to get in early in the journey.”

Cultural Competency / Indigenous Awareness

A common thread throughout this research has been the lack of knowledge many service providers, and their representatives, have about Indigenous peoples. Though courses on cultural competency are commonplace, there is still a notable dearth of basic information about Indigenous histories, experiences and realities. As stated previously, some non-Indigenous service providers operate with ignorance of First Nation and Aboriginal communities, which has led to fear and a denial of services. One participant stated,

“In some cases I don’t know if it’s lack of cultural safety. They don’t know the history of First Nations people. They don’t know there will be a breakdown of communication with them based on the way they interact with patients in the hospital. Because of that, there is no cultural safety; I don’t know how much is going to change. I’ve seen racism - a lot of it when I was there. It was right down to the CCAC staff at discharge. Then admitting doctors and nurses; I saw a lot of racism. Very dismissive. If someone’s going for pain, for example, they think they’re only there drug-seeking. That wasn't the case. There was someone not investigated properly and this gentleman had a severe case of rheumatoid arthritis. It was never investigated. He went to the hospital for several years until finally a doctor took it seriously and investigated. Nobody took him seriously - they all thought he was looking for drugs.”
The presence of racism is one that looms large over Indigenous peoples and their experiences with the health care system. This a reality that has come to be expected by Indigenous peoples in their health care encounters and this can influence decisions about care. Participants shared,

“Most of the time they don’t want to die in hospital ...you hear a lot of stories and bad treatment... like racism going on and the events that go on there, at least from their point of view so they are happier to be at home.”

“...the hospice closest to us is about an hour away and not really First Nation friendly, not disrespectful but not educated enough.”

This is complicated by mistrust of institutions and western medicine felt by Indigenous peoples. Historically, one of the prominent sites of colonization has been through institutions that Aboriginal peoples were forced to attend. Most people are aware of residential schools and their devastating effects, impacting generations of communities and their emotional, mental and physical health. Canadian health care institutions and their representatives have historically used western medicine as a way to control Aboriginal communities, including removing people to far away institutions where they saw fit. Traditional Indigenous knowledge, such as medicines, were denigrated by western science, while Indigenous spiritual practices, an important part of healing, were outlawed and continue to be unwelcome in some health care institutions.

At the end of life, spirituality becomes an important consideration for all peoples. There continues to be ignorance displayed by health care representatives towards Aboriginal peoples concerning spiritual matters. Palliative care is not the place for basic education concerning complex Aboriginal spiritualities and yet it happens out of necessity. Participants said,

“To be with their family in their own surroundings...their traditional care and often they don't want people to know; they are embarrassed. I inquired about one of my patients who was holding his own but the staff member told me that the family wanted to smoke so I said no they want to smudge which is similar to you and a rosary. I had to educate them as they jumped to conclusions. Education part is still part of it all.”

“Safety, particularly cultural...encourages cultural competency training; spirituality needs to be open and ask, and listen, listen, listen. They take their time in processing information or questions and when they respond they will give you in most cases their true thoughts and perceptions. Non-Natives may think the native person is deaf or stupid or does not understand, but they are taking to process and give an accurate answer...”

“When it comes right down to it, people at the end of life; reflecting on their life. Spiritual things become really highlighted and important. Culture is so important in the Indigenous community. People who you didn’t think it would be important, becomes very important. To have cultural and spiritual needs met is important. Sometimes you can’t because of your illness; either the mind isn’t there or the body isn’t strong enough so it’s very important to have that advocate before you can no longer participate...to have a connection to make things run smoothly towards end of life.”
The historical mistrust of health care institutions and their representatives has lasted until now, as the Canadian health care system has not provided equal access to, and funding of, Aboriginal health care services. This long history of mistrust impacts the ability to deliver and receive palliative care. Participants stated,

“There are generations of mistrust of western medicine of which we are trying to break the barriers here in SOAHAC, but we’ve by no means achieved our goals yet. To get palliative care in the home... it’s tough to break those barriers because there is a lot of mistrust there.”

“I have clients who refuse to let CCAC in the house because of the way they speak to the family. I had a patient yesterday...CCAC come out once a week, the patient is stable and the son asks why do they come out once a week... he feels it is just to make themselves busy and fill up their time. The Case Worker has to come out a certain number of times for the funding but he feels they are being used for making money; so he kicked them out; he said they did not listen to anything he said... they asked a string of questions very quickly and did not give him time to answer. It was just a bad experience and was not patient centered care...he is very confused and says they did not explain it. I have mixed emotions. Some like it others just want the family...it is the cultural piece...they are not comfortable having them and do not understand the spiritual side... I had this family who had had a bad experience with legal system and to them it just felt like that all over again...they used very authoritative speech which they were just not comfortable with. CCAC does not have cultural competency at all.”

As has been illustrated throughout this report, the lack of Indigenous awareness is highly problematic and has a large impact upon service delivery. Cultural competency training needs to go further and cover Indigenous histories and realities, in addition to cultural knowledge.

**Families Need More Access to Grief and Bereavement Services**

Participants advised that families require stronger support for grief, loss and bereavement. There is support required at the anticipatory stage and then coping with the family’s own grief and loss after the patient’s death. Participants stated,

“[Follow up and bereavement supports] is a big gap we have here – it falls to family / friends / clergy / elders. I am embarrassed that it is not us at the health centre who can provide that.”

“[Follow up and bereavement] does not have CCAC involvement; they’re done when the patient dies and services are pulled out immediately. There may be a rare exception where a social worker is well connected with the family and they may do a follow up.”
Providing Culturally Safe Services

The participants in this research brought decades of experience in different facets of palliative care to every interview. Every one of them had an understanding of how to improve the experience of palliative care for Indigenous peoples and communities. What follows are some of the ideas they had to make palliative care a more holistic and patient-centred experience for Indigenous patients.

“...a volunteer group in community which would assist. There is a little interest and then it goes away; this happens repeatedly. When we had a lot of deaths last year I reached out to hospice clergy. People are very close so I reached out to other people. It’s just who I know and who I can get help from. If people want to die at home and families agree, but I don’t think people understand what that means and we have families that just disappear. They do a bit and then are exhausted.... We need to have an arrangement with physicians. Doctors are not keen to get orders from outside groups etc. I thank that would be awesome....The workers are often related to those who are dying, so perhaps it would be good to have PSWs from other reserves to take the pressure off.”

“A social worker absolutely has to be part of it, some kind of Counselor or a Psychotherapist. Social Worker and a Case Manager and we absolutely need someone who can take care of spiritual care, a traditional healer in particular, or it might also be an Elder. There are a lot of religious backgrounds so someone who is aware and ultimately there for spiritual care; and the medical folks of course. The social worker could also have the case manager role.”

“The nursing component for palliative care is really important, also an outreach doctor and some nurses who work with him; continuity and trust is needed to build a relationship with family... someone to sit down and open up to otherwise it is not holistic palliative care.”

“I would love to see a doctor to do palliative care, 2 Nurse Practitioners (RNs to work with him) palliative nursing teams – 4 teams with 3 [people] on each team so there is continuity of care with clients...establish trust and build relationships, communication and continuity of care. Make sure there are resources...PSWs to do the care; RNs can do more than RPNs. Communication is key. Mobile care teams to have a team responsible for talking to an outreach doctor about meds etc. In the past if I needed a pain pump I would get it at the end of that day, now I have to wait for a week, the person might be dead by then.”

“A focus group to help make the transition a little easier and if there was funding what would you like to have out here. It all boils down to funding and finding out what the community is really looking at with the Focus Group...this is what we are interested in and the care we want, even palliative beds at the long term care next door as its close...anything off reserve is a transportation issue, keeping everyone close being the family and not the care giver. A Hospice Palliative Care unit would be fabulous but I am not sure that we get enough palliative cases. Sometimes the family is scared and if they end up not coping they go into hospital.”

“I would love to see visiting professionals on site...our own doctor. A lot of people go to SOAHAC and we are fortunate and we have had many of our clients transfer through to SOAHAC. The NP who will do home visits if the people can’t get out...she’s ideal for us in palliative or those with mobility or family challenges. I would love to see a lump sum of money and then the communities determine
how that's used...wouldn’t it be fantastic if we could use community philosophy to how that money is distributed?”

“Have a circle of care with whomever the client wants...have a meeting to decide and get everyone in the loop, follow up and open communication. In the Aboriginal culture, everyone in the family is involved...I always go to funeral to be respectful. If there was open communication the process would be easier for the family.”

“When this program gets off the ground, a huge part will be education to mainstream providers about the decision of this program to identify people to help them have options and respond to protocol. There is no room for cumbersome referral... it has to be a very responsive, dynamic type of process.”

“An Aboriginal organization to take on the care, regardless of if they have a physician they are following. To be on reserve and culturally competent...understand Western Medicine compared to several different beliefs - not even just Indigenous beliefs, there are several different variations that a team would need to be aware of. To be complete, there needs to be more than one physician; 365/24/7, so people are able to switch off. A lot of it requires medications, which a RN cannot do so there is a need for a physician to be on call. The second is either a nurse or RPN to do the day to day in the home. Dream team would have social worker on call to deal with some of the issues that come up. Cost analysis: one day at the hospital versus one day in home. .... it’s a lot cheaper to afford a team on reserve....A logical thing would be to have the team based out of SOAHAC. Communities are aware of what we do and we’ve been established a long time.”

“Another thing to mention which I haven’t yet is a traditional healer...many people we interact with are a mix of western and traditional, so to have the traditional healer on the team would be beneficial.”

“One thing to be put into the team is that this will take time. To spend time with families as it is not just about crisis but a good palliative care team will get to know the team not only in the worst times, but at the times when they are stable as well. So it is not just putting out fires, but they are there to help in the whole journey.”

“I’m surprised we don’t have an Aboriginal agency of PSWs, RPN, etc. In London we have different cultures - Cree, Iroquois, Ojibwe. We’re all First Nations but still have our own ceremonies. I think we should be able to provide that.”

“...the government provides hospice a certain amount, the hospital needs to raise money. Our hospital I think needs to raise $1million a year for hospice money. Our job as the LHIN is where to best put funding. What we’re finding with hospice is that a whole new building for hospice is not cost effective so that’s why our building is in Sisters of St. Joseph. My question is: why can’t we take those dollars and put two beds in the community. The community might need to raise money to keep the beds open. Huron area doesn’t have enough hospice patients for a separate person, and it’s a huge geographical reason. Why would they go 50 km away when we can be creative by going to a nearby nursing home?”
PATIENT EXPERIENCES

The purpose of palliative care is to ensure that those patients who are near the end of life have the care and services they need to pass away at home. However, this has not been the experience of Indigenous peoples who are palliative in southwestern Ontario. In order to improve this experience, and to place Indigenous peoples at the centre of this experience, a number of patient journeys/experiences have been collected. It is these experiences, coupled with the guidance of local Indigenous communities, which must inform future change to palliative care for Indigenous peoples in southwestern Ontario. The following stories need little introduction and speak for themselves.

“I had one woman who died in her daughter’s house with a rosary on one side of her and medicine bags on the other side – she had both. Sad to say I had to hound the priest to come and give her the last rights. The priest was reluctant but came.”

“The client was the grandmother of our administrator and one of her nephews was a physician who had worked in the community and had moved to Sioux Lookout and he came down to see her and was making suggestions, but the nurses were just not coming in. The family called us once because they could not get a nurse - she said she had been in today and was not going out again. I had a conversation about our administrator’s grandmother, then we went for a meeting with CCAC and the administrator, who had to recount what had happened which was very difficult for her. The case manager commented that I looked upset and frustrated; she told me that my expectations and standards are too high. I said everybody deserves high standards of care and my nurses are expected to give high standards. I am an old nurse.”

“...one of our clients who was palliative was in rapid deterioration and her daughter took time off work and the son was living there. Visiting nurses came in for pain management and support workers gave a break in housekeeping. There’s a program in place here where people get assessed for overnight from EPSW, which are specially trained PSWs provided through a visiting agency for overnight palliative help. The problem was the referral for that piece came in on a Friday and it took over four days for the family to get the service, so by the time they got service it was only for one night. The other problem was that the family was not able to contact the visiting nurse when the client needed meds...the agency said “the nurse is unavailable”. It has since been addressed, but the agency did not say “the nurse will call you,” so the family decided to take her to Emergency.”

“There was a woman with end stage liver failure. I visited her in the home, she was very sick, and wasn’t receptive to me calling an ambulance but did agree to a taxi (she was only discharged 2 days before and we weren’t involved in the loop). I tried to speak to family members and tell them she was critically ill. She was agreeable to going in a taxi and was admitted. She did not want any intervention and died soon after. That did not go well at all and patient choice was taken into account – it was discussed and she chose not to. I’m not sure there was time for anything else – such as to go back home and there was nothing traditional...all the focus was on life saving measures. It came from a medical perspective and a reasonable one, but not a holistic one.”

“I had a patient who died at home and it was ideal. He lived with family members who were very good at advocating for themselves, had pre-existing relationships (which is a strength) with our clinic, and the patient had experience with CCAC with some minor support. There was a good family network and time was spent with the patient. They had made the pre-arrangements with the
funeral...knew everything. I was on board, communication with CCAC was perfect, I got calls from nursing staff in the home for the orders and I was on call for the death certificate. That is the one time that everything went well due to a pre-existing relationship and really good communication.

“I had a man in the hospital and wanted to go to LTCH, as it was too much for his wife but he was told there was a waiting list and couldn’t go in. The Care Coordinator got him discharged and he was sent home rather than to LTCH...the wife said he was just told he had to come home and she said she felt railroaded. He only lasted two days...when the wife called me she said that the lady from CCAC said her “husband is actively dying”. When I arrived at the house the Care Coordinator and OT were getting into their cars and when I went in he was chain smoking. She said “is he dying?” I said yes, and told her to call her son and daughter and get them here and then I sat beside him and held his hand...he went with me then...I had them all there and we hugged as he went. When I came back I called CCAC and blasted her and said, how can you leave that woman in the house on her own? The woman said nothing and in the end she said, I knew you were coming.”

“I have a friend who’s a hunter. My friend [in LTC] cannot have the venison dinners I take in to him, as I was told the menu at LTC was set by the government and cannot change, so I can’t give him food, even if its prepared by the butcher...I cannot even give 4lbs of ground venison so they can make chili to feed 60 people. My friend is a Residential school survivor and he is again being told what he can and cannot do by the white man…it is wrong. The LTC facility here is run by an outside agency so they control it all...”

“We had a situation where we had a client who was end of life (waiting for LTC) and in the meantime we put in a request with South West LHIN for funding to increase the amount of time we had PSWs in there for him. It came back as why wasn’t CCAC putting services in...so we told them and that hit the fan as the LHIN did not authorize CCAC to pull PSWs. So this might be a really good opportunity to get PSWs back from an agency.”

“I had a residential school survivor from a northern community who came to London. He had personal issues in his life 10 years ago and I had not heard from him for awhile until he contacted me. He had a number of conditions...was at the hospital where his doctors considered him palliative. I went to visit him and he was lucky to be alive and was not expected to live long. He married a non-Native woman who didn’t understand his culture and was not cooperative around his last wishes...I think part of him contacting me was to get another person in there with the wife, so my role was to make sure he got what he wanted which was to go home to his community in the north. I did the best I could to work with the family and advocate with him... connect his family to the north. There were a couple things I noticed...they felt isolated in the hospital and not connected to cultural support which his wife wasn’t supportive of either. The hospital probably asked her (the wife) about these things rather than him and she had a different perspective. We got him into long term care but he wasn’t expected to live long (heart issues)...his wife was encouraged to let him go to Oneida LTC, which is where he went. He lived out the last days of his life there, so he got to speak to some of his family here before he left... cousins and things...they had a place for him, essentially and that’s where he had his last days. As I looked at how that whole journey went, there was nobody involved, he wasn’t a patient at SOAHAC, or else I would have followed up sooner, he wasn’t connected to culturally relevant services because his wife wasn’t supportive of his cultural background and she was making decisions for him. This is one case where the non-Native partner was not advocating for him when he really just wanted to go back to his home to his community and culture which was
very important to him. As a counsellor, I had had a longer relationship with him years ago...he had lots of challenges and conflict with the family and he needed someone to meet his spiritual needs at end of life. There were no transportation arrangements because he had been disconnected from his community for so long.”

“We had a senior being financially abused by her two sons. We were aware, but unable to do anything about it and then her health deteriorated – she was hospitalized...so once she was home we were able get someone into the home every day. The nurse has kept close case management with this person, who now requires home services. We go three times a week and both sons know we are watching them and they are not trying anything anymore and we have pulled them in to assist with her care. They are living very harmoniously now and both boys have specific jobs to do to help their mother. I developed an Elder abuse committee on Walpole Island. We have had a number of events to raise awareness of this issue. It is difficult to intervene without support from the client. In this case, we were just in the home and were able to see what was going on and protect her. It was mostly our nurse; she slowly asked them to do more and more; one does medication and appointments, the other does entertainment, TV shows, bingo etc. It is working, makes them accountable and now they are living in harmony, where it used to be chaos.”

“I remember one case that the communication with the family was not good; it was a patient who was being discharged to come home and the family understood he was palliative but CCAC said he was not palliative yet. So the family wanted a high level of PSW support, which they are eligible for if they are palliative, but not if they are not palliative – it took a lot of negotiation on behalf of our team here to sort it out and get it organized. If the family didn’t have our support, I think it could have gone bad.”

“In some cases when someone is dying at home, the system cannot put in enough formal supports; it has to be a partnership with the family and care providers. I can think of one person who is close to terminal; she has no family and will be very reluctant to go anywhere to die. She has oxygen and we have persuaded her to have a PSW in her home to help a little bit...but she will not be receptive to what the system has to offer. It has the potential to be a disaster and I know her choice will be to die at home, so I don’t know how that’s going to look; not good.”

“When I had a team in there and people died at home, it was a good death. I had a gentleman who was looked after by a sister and brother in law. They said they felt they could not do it anymore and could we find a place for him, but there were no beds or anywhere to go. I had a good relationship with the Care Coordinator from CCAC then, so I called her and she went to the hospital and found a bed for him. He had a good experience and passed away there, but there would be more opposition to it now. A big obstacle is the seniors... they get boomeranged back out of the hospital. I had one guy who was sent in the ambulance and they [paramedics] wanted him to take clothes to come home in.”

“...a few weeks ago I had a patient on CCAC, not doing well, no family support because of alcoholism...the families turned their backs on him. PSW could only work a certain amount of hours. He needed 2 PSWs, three times daily because he’s non-weight bearing. They were overwhelmed and calling me with problems. I referred him to palliative care. He’s not interested in any more cancer treatment. The Edith program referred him and the PPS scale assessed him, as they needed a certain percentage for daily care. They did the scale and said he’s not there yet and offered an RPN once a week. I
said he needs PSW care round the clock. He was filled in urine and feces, top to bottom at 10am; I couldn't work with him, I had to give a bed bath, something I haven't done since nursing school. I needed CCAC to come in and I met with the family. He died a week later. He went to the hospital and died there...he was at the end. This just happened. He's in the obituaries right now. The CCAC kept saying he needed to be more palliative at the end. He died a week later - how close does it need to be? This stigma continues. They had things on file like "alcoholic", don't go after 6pm, and don't go inside if there are a lot of cars in the driveway. He had a label as a difficult patient."
DISCUSSION

Indigenous people across Canada who are living with advanced, progressive, chronic, and terminal illness wish to receive palliative care at home or in their First Nations or Aboriginal community. This population includes people of all ages with any diagnosis who would benefit from a palliative approach to care, especially in the last year of life, as well as the family and community caregivers of that person. When individuals wish to die at home, palliative care extends to include end of life care.5

Ontario has made significant commitments and investments to support the development of a comprehensive strategy for palliative and end of life care in the province. These commitments include improving health outcomes for Indigenous people in Ontario including fair and equitable access to high quality culturally safe palliative care.

The discussions with more than 25 key informants, two focus groups as well as the Reference Panel in this first phase of the South West Indigenous Hospice Palliative Care, substantiated what previous studies have already documented. First and foremost, Indigenous people, First Nations communities and Aboriginal organizations in the South West LHIN solidly affirmed their readiness, capacity and desire for Indigenous palliative care services based on principles of self-determination, equity and social justice intended to improve quality of life for Indigenous people who are dying and their families. Dying at home is not only the preferred option for most Indigenous people; there is also a strong economic rationale for providing at home palliative care. Today, Indigenous people are dying in the hospital, which is the most expensive setting of care and not an efficient use of health services. Caring for terminally ill patients in an acute-care hospital is estimated to cost over 40% more than providing care in a hospital-based palliative-care unit, more than double the cost of providing care in a hospice bed, and over 10 times more than providing at-home care (Office of the Auditor General of Ontario, 2014).

In the Patients First Report released December 2015, the Ministry of Health and Long Term Care is taking steps to make structural changes to home and community care but it is imperative that the specific input from the Indigenous population informs the Hospice Palliative Care approach for that population. The current model implemented by the South West CCAC is not effective with the Indigenous population and particularly with the First Nation communities regarding palliative and end of life care.

As the Honourable John Fraser stated in the March 2016 Palliative and End-of-Life Roundtable Report it was clear that not all Ontarians have the same access to Palliative and End-of-Life Care and this was corroborated when service providers described the current state of Palliative Care Pathways for Indigenous People in the South West LHIN.

Ontario’s publicly funded palliative-care services are mainly used by cancer patients, even though as many people die each year from advanced chronic illnesses that would also benefit from palliative care, including heart disease, stroke and chronic obstructive pulmonary disease (Office of the Auditor General of Ontario, 2014).

5 Kelly, Mary Lou and Holly Prince. A Framework to Guide Policy and Program Development for Palliative Care in First Nation Communities. Lakehead University, 2015.
There is a high burden of chronic disease within the Indigenous population in the South West LHIN which is well known to the First Nation Health Centres, Friendship Centres, Kii-Kee-Wan-Nii-Kaan Southwest Regional Healing Lodge, Métis and SOAHAC, requiring culturally safe care for the Indigenous people. Participants shared more than 40 examples of chronic patients who became palliative and wanted to die at home, however the South West CCAC acknowledged that they had only provided end of life care to 2 or 3 patients in the past two years.

Many explanations were provided for the lack of equitable access for Indigenous people in the South West LHIN. Some rationales were systemic barriers, many were policy related, a few were human resources, some were jurisdictional and many were associated with cultural competency. The common undertone that emerged was that the majority of issues precluding access to quality palliative and end of life care were preventable. Stakeholders described numerous meetings held to resolve these issues over the past few years.

A theme which emerged was the existing Hospice Palliative Care program is uncomfortable working with many Indigenous people in the South West LHIN. There was a lack of understanding of mental health issues, addictions, historical trauma, the impact of unexpected and accidental deaths, and the high prevalence of death within the community impacts and how this may compound grief and bereavement. There was more concern expressed for the needs of the service provider than for providing patient-centred care.

As noted in the Palliative and End of Life Care Provincial Roundtable Report March 2016, the simple fact is that not enough patients and families receive the palliative care, support and services they need as early as they need them, and in the most appropriate setting. This is particularly true for the Indigenous population in the South West LHIN.
As noted in the introduction, this planning project has been identified as a priority for a one-time investment through the Aboriginal Health Committee for the South West LHIN to enhance and support the development of an Indigenous-informed approach to address the Hospice Palliative Care and End of Life care for Aboriginal and First Nations communities located within the South West LHIN. At the system level, the LHIN, in partnership with the CCAC, have been tasked with developing a comprehensive Hospice Palliative Care System that will address the needs of populations across the South West LHIN.

Phase one of this eighteen month project was tasked with engaging with Aboriginal stakeholders and service providers to undertake a readiness assessment utilizing applicable resources from the Lakehead University research project entitled “Improving End of Life Care in First Nation Communities”. The following recommendations for an Indigenous Hospice Palliative Care program have been based on the findings of a health infrastructure assessment, readiness assessment, focus groups, key informant interviews with service providers and meetings with stakeholders and the Reference Panel.

**STRENGTHENING SERVICE CAPACITY**

Participants in the South West Indigenous Hospice Palliative Care planning process endorse a unique philosophy, definition, and, community-based process for providing palliative care in Aboriginal and First Nations communities that is distinct from a westernized, medicalized or urban model of palliative care. The program must be based on Indigenous understandings of health, illness, birth, and death which differ across communities and linguistic groups. The Indigenous Hospice Palliative Care program must be based on Indigenous control and implementation of a community capacity development approach that emphasizes the engagement of Indigenous community members, and incorporates community culture, strengths, and resources.

The South West Indigenous Hospice Palliative Care Program will provide Indigenous people the choice to receive palliative care in the setting of their choice, including the choice to receive palliative home care services where they are surrounded by family, community, and culture.

**Recommendation #1:** That the South West LHIN fund an Indigenous Hospice Palliative Care inter-professional team (collaborative) at SOAHAC to improve patient and system-level outcomes to be composed of:

- Registered Nurses
- Nurse Practitioners
- Social Worker with experience in grief and bereavement counselling
- Mental Health Worker
- Traditional healer
- Personal Support Workers
- Occupational Therapists / Physiotherapists
- Physician(s)

The team will service all of the South West LHIN Indigenous people regardless of whether they are rostered patients.

*NOTE:* These positions could be transferred to SOAHAC from CCAC resources under the current reallocation through the South West LHIN as well as investments from MOHLTC in End-of-Life Care.
As an individual requires palliative care or nears end of life, this has a tremendous impact on family members and caregivers. The act of providing care for a loved one has an undertone of the grief and bereavement to come. Negotiating a complex health system during this difficult time can be challenging. There is a widespread feeling that a system designed to make the final stages of life as easy as possible is often difficult to find and frustrating to navigate. An Aboriginal Patient Navigator is beneficial in order to provide advocacy, referrals and supports. This process is formalized when the palliative care patient is diagnosed with cancer, however is limited on other types of chronic diseases.

**Recommendation #2:** That additional Aboriginal Patient Navigators are hired to provide broad community outreach and case management through the Indigenous Hospice Palliative Care program. The goal will be to work with palliative clients and their families to introduce the Indigenous specific services, traditional practices as well as linkages to mainstream services that will bridge the gaps for positive patient health experience.

The current state analysis confirmed the urgent need for Palliative and end of life care be provided by an Indigenous Community Health Service Provider that can provide integrated services. Numerous examples of patient experiences were shared during the current state analysis, whereby the existing system delivered by the CCAC is simply not available for Indigenous people living in First Nations in particular, and the urban setting. This was confirmed by the CCAC when they stated they had only had 2-3 palliative care cases in the past two years whereas participants in this report advised of at least ten times that number of requests for end of life services in the past two years. Under the proposed structural changes in the recent Patients First: A Proposal to Strengthen Patient-Centred Health Care In Ontario, the MOHLTC is transferring direct responsibility for service management and delivery from the CCAC to the LHIN. To improve home and community accountability and integration of services especially care coordination.

**Recommendation #3:** That CCAC Care Coordinators working with Indigenous peoples come under SOAHAC to ensure consistent care.

**Equitable Access to Services**

Palliative care is not only intended to help people die in comfort. Its goal is to help people facing a life-limiting illness to live as long and as comfortable as possible, and enhance their quality of living and dying. For that reason, the earlier palliative services can be delivered to patients who have been diagnosed with a life-limiting illness, the better for their health.

Earlier identification of disease trajectory and subsequently earlier identification of Indigenous people as “Palliative” will be a key role of the Indigenous Hospice Palliative Care Team. It is important to provide services and resources to the palliative care patient sooner. The Indigenous Hospice Palliative Care program will work more closely with other Health Service Providers to identify patients with chronic illness that may sometimes receive palliative services. Chronic disease sometimes is palliative. The role of the Indigenous Hospice Palliative Care will be to establish guidelines and eligibility criteria that is consistent with the unique needs of the Indigenous population.
Participants indicated one method for identifying patients earlier in the disease trajectory is to have the First Nations Health Centres and SOAHAC who are managing chronic diseases, take the lead in screening and diagnosing Palliative patients (chronic becomes palliative).

**Recommendation #4:** The Indigenous Hospice Palliative Care Program will establish early relationships with chronic patients and health service providers to ensure earlier identification of disease trajectory and earlier identification of Indigenous people as “Palliative”.

The Indigenous Hospice Palliative Care program will allow for customization of the eligibility criteria and policies to address diverse patient and community needs. In particular, the program will be responsive to the historical trauma, the impact of unexpected and accidental deaths, and the high prevalence of death and impact those experiences have when working with palliative care Indigenous clients and families. Policies will be designed to accommodate a patient-centred approach to Indigenous Hospice palliative care.

**Recommendation #5:** That the Indigenous Hospice Palliative Care Model be designed on low threshold principles intended to screen patients into the Indigenous Hospice Palliative Care Program rather than screen them out.

Indigenous palliative and end of care clients are not receiving the support they need, and often must leave their communities – where they feel culturally safe and respected – to receive palliative care far from family based supports including assessments and palliative care treatment.

**Recommendation #6:** That additional transportation services are provided through South West LHIN funded Community Support Services to enable Indigenous patients and escorts attend palliative care appointments.

**Advance Care Planning**

Advance Care Planning helps individuals think about and communicate their values, beliefs and wants for end of life care. These are difficult conversations to where individuals contemplate their wishes, particularly around medical procedures and/or interventions, and share them with family members. It also involves selecting a Substitute Decision Maker. The public and Indigenous peoples are unaware of Advance Care Planning.

While Advance Care Planning conversations are often difficult and emotional, they make it much easier to provide patient-centred palliative care. Advance Care Planning informs patients' health care providers and lays the groundwork for patients to receive not only the services they need, but those they want.
While it’s difficult and emotional, the earlier Advance Care Planning happens in the palliative care process (i.e. 6 months prior to end of life), the more prepared and supported the family is for end of life process. Advance Care Planning works better when there is a strong relationship built with the palliative patient and family.

Conversations between care providers, patients and families should include discussions about palliative care as well as Advance Care Planning.

**Recommendation #7**: That Advance Care Planning be a key component of the Indigenous Hospice Palliative Care Project utilizing tools designed by the Improving End of Life in First Nations research project as guidelines.

**Improving Caregiver Support**

Recent studies support that home visits from primary care providers, nurses, and other palliative team members help patients remain with their families and in their home longer. Home visiting reduces burden on their health and the time and energy it takes to travel to appointments. It can help manage expectations and help family members cope with changes. It can also reduce unnecessary visits to the hospital or emergency department.

**Recommendation #8**: That Indigenous palliative care patients receive home visits from health care providers from their Indigenous hospice palliative care team on a regular basis. This will include follow-up grief and bereavement supports for family members following the passing of the palliative patient.

Additional supports would help caregivers avoid burnout. Throughout the palliative care process, it is critical that caregivers have access to respite services so that they can take breaks and manage other responsibilities. This would include regular access to Personal Support Workers and e-Shift.

**Recommendation #9**: That Indigenous palliative care patients receive e-Shift at end of life.

**Recommendation #10**: That Personal Support Worker services are increased in First Nations, which might be addressed in the Indigenous Hospice Palliative Care model directly at the community health centre either through adding more hours to the First Nations agreement through their existing LHIN agreement and/or by adding Personal Support Workers to the SOAHAC agreement (to be determined) and transferred to the First Nation.
More Health Care Providers should be knowledgeable about Palliative Care

It is important to ensure that all Indigenous patients have access to culturally appropriate and safe palliative and end of life care, including those from urban, rural and remote communities, and including various cultural, faith and linguistic groups, vulnerable populations (e.g., people who are homeless, have mental health or addiction issues) and people with disabilities.

The Indigenous Hospice Palliative Care Program will be built on teamwork/collaboration and partnerships across organizations and jurisdictions both within the Indigenous community and between the Indigenous community health care providers and external health service providers (hospital, home care, cancer care, etc.). The program will ensure effective and efficient protocols are in place across organizations and jurisdictions for communication, discharge planning, care planning, case conferencing, and sharing of important information in a timely way. It will collaborate with cultural, traditional, and spiritual helpers/healers to ensure they are included in the Circle of Care. The Indigenous Hospice Palliative Care Program will provide training and support for all external health care providers (e.g. hospital, home care, palliative care) who provide direct care to people living in the First Nation or Aboriginal communities, including knowledge of community values and protocols (service, communication, advance care planning, and end of life conversations). This training is not standardized and must be guided by all the communities served (e.g. urban, Métis, First Nation).

Recommendation #11: That the South West LHIN, South West Palliative Care Network and all service providers working with palliative clients and families be educated on the complexity of Indigenous Health issues, respect Indigenous rights to determination in health and be trained on Indigenous cultural safety.

Ontario and the South West LHIN do not have enough health care providers who are knowledgeable about palliative care. Communities of practice or new training standards to improve the capacity of physicians, nurses, personal support workers, pain and symptom management consultants, and others to provide palliative care would be beneficial.

Recommendation #12: That up to date Palliative care training be provided for all health care workers involved with the Indigenous Hospice Palliative Care Team within two years.

Supporting Hospice Care

Participants expressed the need for appropriate hospice space where traditional practices (such as smudging, cedar baths and other ceremonies) could be practiced when providing end of life care. As part of the 2016 Budget, Ontario is investing in hospice for palliative and end of life care. This would be an opportune time to invest in Indigenous hospice and palliative care bed(s) as part of this initiative.

Recommendation #13: That an Indigenous Hospice Bed / palliative care bed that accommodates diverse Indigenous spiritual end of life understandings be established.
Phase Two South West Indigenous Hospice Palliative Care Program

Phase two of this eighteen month project is tasked with implementing the findings of this needs assessment.

**Recommendation #14:** That the Indigenous Hospice Palliative Care Program guidelines are developed utilizing applicable Improving End of Life in First Nation resources, including:

- Approach/Model for the Indigenous Hospice Palliative Care program;
- Mission and vision statement of the program;
- Eligibility criteria and referral process;
- The Indigenous Hospice Palliative Care pathway, which may include:
  - Client identification
  - Case conferencing
  - Client assessment tools and processes
  - Education and support for family and health care providers
  - Communication and coordination
  - Respite care and volunteer program
- Roles and Responsibilities of inter-professional team members;
- List of specific services.
### APPENDIX A - GLOSSARY

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
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<tr>
<td><strong>Acute-care hospital</strong></td>
<td>A hospital that offers short-term, intensive inpatient treatment and care to patients with serious health problems. An acute-care hospital can provide palliative care to patients in a designated palliative-care unit or in regular beds throughout the hospital.</td>
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<tr>
<td><strong>Advance Care Planning (ACP)</strong></td>
<td>A process to communicate an individual’s values and wishes to others regarding future health-care preferences in the event that the patient becomes incapable of making health-care decisions.</td>
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<tr>
<td><strong>Alternate level of care (ALC)</strong></td>
<td>A designation that is applied when an individual is ready to be discharged from hospital, but is waiting in a hospital bed for post-discharge care to be arranged, such as home-based palliative care or placement in a hospice or long-term-care facility.</td>
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<tr>
<td><strong>Bereavement</strong></td>
<td>The term bereavement, takes account of the unique individual grief experience of the bereaved person, through the anticipation of death and the subsequent adjustment to living following the death, of someone significant (Stroebe et al, 2008; Strada, E.A. 2013; Christ et al, 2003).</td>
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<tr>
<td><strong>Canadian Hospice Palliative Care Association (CHPCA)</strong></td>
<td>A national association that advocates for good-quality palliative care, including end-of-life care. This includes promoting public policy, education and awareness of palliative care.</td>
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<tr>
<td><strong>Canadian Institute for Health Information (CIHI)</strong></td>
<td>A not-for-profit organization created by the federal, provincial and territorial governments that collects and analyzes information on health-related matters in Canada, including palliative care. CIHI’s data and reports may be used to inform health policies, support the effective delivery of health services and raise awareness among Canadians of the factors that contribute to good health.</td>
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<tr>
<td><strong>Canadian Institutes of Health Research (CIHR)</strong></td>
<td>The government of Canada’s health research investment agency, which works to create new scientific knowledge and to enable its translation into improved health, more effective health services and products, and a strengthened Canadian health-care system. It is composed of 13 institutes and provides leadership and support to health researchers and trainees across the country.</td>
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<tr>
<td><strong>Canadian Medical Association (CMA)</strong></td>
<td>A voluntary professional association that, among other things, advocates for physicians and patients in Canada.</td>
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<tr>
<td><strong>Cancer Care Ontario and Regional Cancer Programs</strong></td>
<td>Cancer Care Ontario is the provincial government agency primarily responsible for, among other things, improving Ontario’s cancer and chronic kidney disease health systems, including access to palliative care for these patients. Its palliative-care services program is provided through 13 Regional Cancer Programs. Its palliative care services program is provided through 13 Regional Cancer Programs.</td>
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<td>Term</td>
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<tr>
<td>Cardiopulmonary resuscitation (CPR)</td>
<td>A series of lifesaving procedures that include chest compressions to assist with blood circulation to the heart and brain, improving the chance of survival for patients who experience cardiac arrest.</td>
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<tr>
<td>Centre for Education and Research on Aging and Health (CERAH) Indigenous Peoples Health and Aging Division</td>
<td>CERAH’s Indigenous Peoples’ Health and Aging Division seek to promote culturally relevant research, education and health care services for Indigenous people in Canada, especially in the Northwestern Ontario. CERAH has a 2 day First Nation based Palliative Care curriculum, ‘Palliative Care for Front Line Workers in First Nations Communities.</td>
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<tr>
<td>Community Care Access Centres (CCACs)</td>
<td>There are 14 Community Care Access Centres across the province, one in each LHIN. The CCACs accept referrals and determine eligibility for patients requiring home-care services, such as in-home nursing and personal support, or a hospice. The CCACs arrange for these services, which they provide directly or through external service providers. As well, the CCACs provide referrals to other community-based support services, such as those offering transportation.</td>
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<tr>
<td>Coordination of Care</td>
<td>An approach in which all members of the medical team work together to plan for a patient’s care in the hospital and for discharge.</td>
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<td>Declaration of Partnership</td>
<td>The short name for the 2011 vision for palliative care in Ontario: Advancing High Quality, High Value Palliative Care in Ontario: A Declaration of Partnership and Commitment to Action. This document was developed by the Ministry of Health and Long-Term Care and about 80 stakeholders. The Declaration of Partnership outlined goals for a palliative-care system, and included over 90 commitments by stakeholders to improve the delivery of palliative care in Ontario.</td>
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<tr>
<td>Dialysis</td>
<td>Dialysis is a medical procedure that cleans your blood when your kidneys can no longer do so.</td>
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<tr>
<td>End of Life Care</td>
<td>End of life care is the term used to describe care that is provided during the period when death is imminent, and life expectancy is limited to a short number of hours or days. The term has been used to describe the last 12 months of life. The clinical program does not use the term in this way.</td>
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<tr>
<td>Home care</td>
<td>Services provided in the home, such as nursing and physical therapy.</td>
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<tr>
<td>Hospice</td>
<td>Ontario has 36 hospices with 271 beds (including four hospices with 11 beds that are not funded by the Ministry) that provide a home-like environment where people with life-threatening illnesses receive end-of-life care. These services include pain and symptom management, and compassionate care during the last stages of a patient’s life. Hospices may offer day programs and other programs such as anticipatory grief and bereavement counselling for family and caregivers.</td>
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<tr>
<td>Hospice Palliative Care Ontario (HPCO)</td>
<td>An organization that, among other things, promotes awareness, education and best practices in the provision of palliative care in Ontario. Its member organizations deliver palliative-care services in Ontario.</td>
</tr>
<tr>
<td>Hospice Palliative Care Provincial Steering Committee</td>
<td>A committee of numerous stakeholders established in December 2012 to guide collaborative efforts to achieve the commitments in the Declaration of Partnership. Members include the Ministry of Health and Long-Term Care, LHINs, CCACs, Hospice Palliative Care Ontario, Quality Hospice Palliative Care Coalition, Cancer Care Ontario, Ontario Hospital Association, Provincial End of Life Care Network, Ontario Long-Term Care Association, Ontario Association of Non-Profit Homes and Services for Seniors, Community Support Service providers, Cancer Care Ontario palliative-care physician group, and the Ontario College of Nurses. The committee reports to the Ministry/LHIN CEO Management Committee, which meets regularly to discuss major system transition issues, strategies and policy changes.</td>
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<tr>
<td>Hospitals</td>
<td>Ontario hospitals may provide palliative-care services to patients in a regular acute-care bed, in beds used for palliative care that may be in a separate hospital ward, or through outpatient services.</td>
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<tr>
<td>Local Health Integration Network (LHIN)</td>
<td>Ontario has 14 Local Health Integration Networks. LHINs are responsible for planning, co-coordinating, funding and monitoring palliative-care services in their regions. LHINs also lead the development of palliative-care models, which set out how palliative-care services are delivered within their area. As well, LHINs flow Ministry funding to palliative service providers either directly (such as to hospitals and some hospices) or through the Community Care Access Centres.</td>
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<tr>
<td>Long-term-care home (LTC home)</td>
<td>These provide care, services and accommodations to people who require the availability of 24-hour nursing care, supervision in a secure setting, or frequent assistance with activities of daily living such as dressing and bathing. LTC homes can provide palliative care to their residents. LTC homes are sometimes called nursing homes or homes for the aged. LTC homes are legislated by and receive funding from the Ministry of Health and Long-Term Care. Ontario has over 630 long-term-care homes with 76,000 beds. LTC homes may provide palliative-care services to residents as needed.</td>
</tr>
<tr>
<td>Ministry of Health and Long-Term Care (MOHLTC)</td>
<td>The Ministry of Health and Long-Term Care has overall responsibility for Ontario’s health-care system, including palliative-care services. This involves establishing overall strategic direction; monitoring and reporting on the performance of the health system; planning for and establishing palliative-care funding models; and ensuring that strategic directions and expectations are fulfilled. The Ministry funds various palliative services through the Local Health Integration Networks, including hospitals, Community Care Access Centres, hospices and long-term-care homes. The Ministry also funds Cancer Care Ontario to fund certain hospital services, including palliative care for cancer and chronic kidney disease patients.</td>
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<tr>
<td>Nurse practitioner (NP)</td>
<td>A registered nurse with additional education and experience, and therefore able to order and interpret diagnostic tests, communicate diagnoses and prescribe drugs to patients.</td>
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<tr>
<td>Occupational Therapist (OC)</td>
<td>Occupational therapy is the art and science of enabling engagement in everyday living, through occupation; of enabling people to perform the occupations that foster health and well-being; and of enabling a just and inclusive society so that all people may participate to their potential in the daily occupations of life (Townsend &amp; Polatajko, 2013, p. 380).</td>
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<tr>
<td>Oncologist</td>
<td>A physician who specializes in treating people with cancer.</td>
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<tr>
<td>Ontario Association of Community Care Access Centres (OACCAC)</td>
<td>A not-for-profit organization that represents and supports the common interests of the 14 Community Care Access Centres.</td>
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<tr>
<td>Palliative care</td>
<td>Palliative care is aimed at relieving pain and suffering and improving the quality of life for people who are living with, or dying from, an advanced illness or are bereaved. Palliative care aims to meet not only physical needs, but also the psychological, social, cultural, emotional and spiritual needs of each patient and his or her family.</td>
</tr>
<tr>
<td>Palliative Care Network</td>
<td>Brings together local stakeholders (such as hospitals, CCACs, community support services, physicians and educators) to improve the quality of palliative care. Membership usually includes individuals or organizations with an interest in palliative care. The networks coincide with LHIN geographic boundaries; currently, 12 of the 14 LHINs have a network.</td>
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<tr>
<td>Palliative-care physician</td>
<td>A physician with competence in the provision of palliative care including the ability to assess and manage pain, and to address psychological, social, and spiritual issues that might arise when treating patients with a terminal illness.</td>
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<tr>
<td>Palliative-care unit</td>
<td>An inpatient hospital unit that focuses on providing care and comfort, including pain control and symptom management, for people who are nearing the end of life, as well as helping patients and their families manage distress and other emotions faced at the end stages of life.</td>
</tr>
<tr>
<td>Palliative Performance Scale</td>
<td>An assessment tool that measures a patient’s functional status and assigns a score. The lower the score, the less time the patient is estimated to have remaining to live. The scale provides a way to measure progressive decline over the course of a patient’s illness.</td>
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<tr>
<td>Personal Support Worker (PSW)</td>
<td>Provides non-medical care to patients, which may include assistance with tasks of daily living such as personal hygiene and eating, as well as homemaking, such as changing bed linens and meal preparation.</td>
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<tr>
<td>Physical Therapist (PT)</td>
<td>Physical therapists (PTs) are highly-educated, licensed health care professionals who can help patients reduce pain and improve or restore mobility in many cases without surgery and often reducing the need for long-term use of prescription medications and their side effects.</td>
</tr>
<tr>
<td>Registered Nurse (RN)</td>
<td>RNs are self-regulated health-care professionals who work autonomously and in collaboration with others to enable individuals, families, groups, communities and populations to achieve their optimal levels of health. At all stages of life, in situations of health, illness, injury and disability, RNs deliver direct health-care services, coordinate care and support clients in managing their own health. RNs contribute to the health-care system through their leadership across a wide range of settings in practice, education, administration, research and policy.</td>
</tr>
<tr>
<td>Royal College of Physicians and Surgeons of Canada</td>
<td>The national professional association that oversees, among other things, the medical education of specialists in Canada, including accrediting university programs that train resident physicians for specialty practices.</td>
</tr>
<tr>
<td>Speak Up</td>
<td>A national campaign developed by organizations including the Canadian Hospice Palliative Care Association and the Canadian Researchers of the End of Life Network to raise awareness of the importance of advance care planning.</td>
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<tr>
<td>Substitute Decision Maker</td>
<td>A person who makes medical decisions and provides consent for treatment or withdrawal of treatment on behalf of another person when they are incapable of communicating their wishes on their own. This person might also be known as a medical proxy, a health representative or agent or a Power of Attorney for Personal Care.</td>
</tr>
<tr>
<td>Terminal Illness</td>
<td>Terminal illness means an incurable medical condition caused by injury or disease. These are conditions that, even with life support, would end in death within weeks or months. If life support is used, the dying process takes longer.</td>
</tr>
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</table>
APPENDIX B - REFERENCES

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Workbook Tools

1. Community Lead Job Description.
2. Community Facilitator Interview questions template.
3. Detailing the Evolution of Palliative Care: Creating a Timeline.
8. Creating a Timeline Template – template for developing community timelines from current state to development of end of life program.
9. Palliative Care Program Guidelines template.
16. Improving End of Life Care Poster Template – poster template for use by First Nation communities.
18. Having Community Readiness for Palliative Care Program Development Worksheets.
19. Terms of Reference for the Leadership Team.
20. Improving End-of-Life Care in First Nations Communities: Palliative Care Program Guidelines; October 28, 2011.
22. Fort William Palliative Care Resource Booklet.
23. Six Nations Long Term Care/Home and Community Care – Palliative Care Program Guidelines.
25. Process of Palliative Care Program Development tree diagram.
27. Care Plan template/example.
29. Embleton, Lori and Harlos, Dr Michael, Winnipeg Regional Health Authority (WRHA). Palliative Care Discharge Planning for First Nations and Inuit Patients Returning to Remote Communities; October 2015.
31. End of Life Care in First Nations Communities Logic Model
32. Palliative Care Program Leadership Team Meeting #1 template.
33. Palliative Care Program Leadership Team Meeting #2 template.
34. Nine Stage Palliative Care Pathway diagram.
35. Palliative Care Program Journey Mapping Workshop #1 agenda.
36. Palliative Care Program Journey Mapping Workshop #2 agenda.
37. Palliative Care Program Journey Mapping Workshop #3 agenda.
38. Implementing the Palliative Care Pathway Action Plan Worksheet.
39. Evaluating the Palliative Care Pathway Worksheet.
40. Documenting the current state – template.
41. Implementing the Palliative Care Pathway Worksheet.
42. Creating Context – Palliative Care for Front-Line Workers in First Nations Communities.
43. A presentation covering working with individuals and families, pain and symptom management, when the time is near, grief and bereavement, relationships and community care teams.
46. Improving End-of-Life Care in First Nations Communities Brochures:
   a. What is Palliative Care
   b. Living with a Terminal Illness
   c. Caring for Someone with a Terminal Illness: Care for the Caregiver
   d. Caring for Someone with a Terminal Illness: What to Expect
47. Supporting the Caregiver and the Family
48. Palliative Care Program brochure template.
50. Community Information Session - poster template.
51. Advance Planning: brochure template.
52. Why Advance Care Plan?
53. Presentation slides on the importance of Advance Care Planning.
58. Sample Forms:
   a. Referral/Intake form
   b. Program Assessment form
   c. Physical Assessment form
   d. Program Care Plan form
   e. Program Checklist for Home Passing
59. Wiisokotaatiwin Program Forms:
   a. Wiisokotaatiwin Program Assessment form
   b. Wiisokotaatiwin Program Care Plan form
   c. Wiisokotaatiwin program Checklist for Home Passing
   d. Wiisokotaatiwin Referral/Intake form

60. Victoria Hospice Society Palliative Performance Scale (PPSv2).

61. Six Nations Shared Care Outreach Team: Care Pathway Description.

62. Six Nations of the Grand River Long Term Care/Home and Community Care: Description of Workplan.

63. Advanced Care Planning Presentation for First Nation Communities: Facilitator's Guide.